



# 8<sup>th</sup> Asian & Oceanian Epilepsy Congress

MELBOURNE, AUSTRALIA 21<sup>st</sup> - 24<sup>th</sup> October 2010

## IBE Programme – Epilepsy & Society

*A one-day symposium on living with epilepsy*

*Thursday, 21 October 2010*

This one-day symposium is for people with epilepsy, their carers, family, friends. And for those professionals working with people with epilepsy in the community, whether that be in the disability sector, education, employment, nursing, and the leisure sector, there is something of interest for everyone.

The day begins with leading sociologist Graham Scambler from University College of London presenting the keynote address on epilepsy and stigma, followed by popular Australian television sports presenter, past Australian Rugby League captain, and author, Wally Lewis, who will relate his own experience of epilepsy spanning some 20 years.

Discussion groups led by national and international experts in their field will examine a variety of epilepsy-related issues that can impact on quality of life including sexuality; memory; sport and exercise; practical ways to manage depression; employment and advocacy issues; sudden unexpected death in epilepsy (SUDEP); and epilepsy and creativity.

International speakers include Dr Elson So, from the respected Mayo Clinic in the US, who will provide up-to-date information on SUDEP - who is at risk and how best to impart this information, and Olympic cyclist and six-times world champion, Marion Clignet, who will reveal how she became an elite athlete with her epilepsy in tow.

Concluding the afternoon session IBE President, Mike Glynn will present the Outstanding Persons with Epilepsy Awards, followed by a book launch by Professor Graham Scambler. Delegates are invited to attend the Congress Opening Ceremony and Welcome Reception.

This will be an exciting and full day for all delegates with the opportunity to meet Olympic cyclist Marion Clignet and Wally Lewis, and others and share your points of view.

Registration fee: US70 For more information and online registration go to [www.epilepsymelbourne2010.org](http://www.epilepsymelbourne2010.org) – IBE Programme

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# IBE Epilepsy & Society Symposium

Thursday 21 October 2010 – Melbourne Convention & Exhibition Centre

8.15–8.45am	Registration
8.45–9.00am	<b>Welcome</b> <i>Mr Mike Glynn, President, International Bureau for Epilepsy</i> <i>Mr Graeme Shears, Chair, Joint Epilepsy Council of Australia</i>
9.00–10.30am	<b>PLENARY SESSION - EPILEPSY AND STIGMA</b> <i>Chairs: Dr Shunglon Lai (Taiwan) and Dr Vinod Saxena (India)</i> <b>Keynote Speakers</b> Understanding 'shame' and 'blame' in social and clinical worlds. <i>Graham Scambler, University College of London</i> My Journey <i>Wally Lewis, TV Sports Commentator and past Australian Rugby League captain</i>
10.30–11.00am	Morning Tea
11.00–12.30pm	CONCURRENT DISCUSSION GROUPS
	<b>Discussion Group 1: Epilepsy and Memory</b> <i>Chair: Jacinta Cummins (Australia)</i> The nature of memory dysfunction in epilepsy and its neurological basis <i>David Weintrob, University of Melbourne</i> Practical ways to live with memory difficulties <i>Michelle Bellon, Flinders University, Adelaide</i> Discussion
	<b>Discussion Group 2: Epilepsy and Sexuality</b> <i>Chair: Christine Walker (Australia)</i> Changes in sexual functioning after epilepsy surgery <i>Sarah Wilson, University of Melbourne</i> Women's reproductive health and epilepsy <i>Beverley Vollenhoven, Monash University, Melbourne</i> Discussion
12.30–1.30pm	Lunch provided
1.30–3.00pm	PARALLEL SESSIONS
	<b>Session 1: Employment and Advocacy</b> <i>Chairs: Robert Cole (Australia) and HV Srinivas (India)</i> Epilepsy and employment <i>Grace Tan, Singapore</i> Advocacy programs for public awareness in developing countries <i>M M Mehndiratta, India</i> Workplace inclusion <i>Wayne Pfeiffer, Australia</i>

## IBE Epilepsy & Society Program cont.

1.30–3.00pm	<p><b>Session 2: Sudden Unexpected Death in Epilepsy (SUDEP)</b>  <i>Chairs: Denise Chapman (Australia) and Yuan-Fu Tseng (Taiwan)</i></p> <p>What is it, and who seems to be at risk?  <i>Elson So, USA</i></p> <p>Global, local and individual perspectives  <i>Rosey Panelli, Australia</i></p> <p>Panel Discussion: Elson So, Rosey Panelli, Jennifer Preston (Epilepsy Bereaved, UK)</p>
3.00–3.30pm	<i>Coffee / Tea break</i>
3.30–4.30pm	<p>CONCURRENT DISCUSSION GROUPS</p> <p><b>Discussion Group 3: Practical ways to manage depression</b>  <i>Chair: Helen Whitehead (Australia)</i></p> <p>The association between epilepsy and depression  <i>Michael Salzberg, University of Melbourne</i></p> <p>An overview of treatment options for depression in people with epilepsy  <i>Simon Jones, University of Melbourne</i></p> <p>Discussion</p> <p><b>Discussion Group 4: Epilepsy and Art</b>  <i>Chair: Graeme Shears (Australia)</i></p> <p>The influences of epilepsy in visual art  <i>Jim Chambliss, Australia</i></p> <p>Winning with epilepsy and calligraphy  <i>K C Janardhan, India</i></p> <p>Discussion</p> <p><b>Discussion Group 5: Epilepsy, Sport and Exercise</b>  <i>Chair: Robert Cole (Australia)</i></p> <p>Excercise, diet and AEDs - from the perspective of an elite athlete  <i>Marion Clignet, France</i></p> <p>Understanding the risks  <i>Ernest Somerville, Australia</i></p> <p>Discussion</p>
4.30–5.15pm	Book launch with Professor Graham Scambler: <i>Social Epileptology</i> eds. Jaya Pinikahana and Christine Walker; <i>Epilepsy in the Family</i> by Suzanne Yanko
5.15–6.00pm	Outstanding Persons with Epilepsy Awards presented by IBE President, Mike Glynn
6.00–6.10pm	Stop Press: Chinese name change will reduce stigma – Anchor Hung, Hong Kong
6.30–7.30pm	Congress Opening Ceremony
7.30–8.30pm	Congress Welcome Reception

Register online now at [www.epilepsymelbourne2010.org](http://www.epilepsymelbourne2010.org)

## Speaker Bios

### Michelle Bellon

Dr Michelle Bellon is a lecturer in the Disability & Community Inclusion Unit, Flinders University SA, and teaches undergraduate and post-graduate topics in 'Disability and Community Rehabilitation' and 'Clinical Rehabilitation'. Her community work and research is predominantly with adults with acquired brain injury in community based rehabilitation, with a strong focus on epilepsy and mental health. Her PhD research explored psychosocial interventions for adults with Posttraumatic Epilepsy (2004), and since that time she has sat on the boards of the Epilepsy Association of SA & NT and Epilepsy Australia.

### Jim Chambliss

Jim Chambliss is a reformed attorney who rebounded from brain injury that caused epilepsy and numerous setbacks in his health and life. He experienced a personal metamorphosis through subsequently discovering an unexpected talent and inspiration for his award-winning visual art. His art and personal story have been published on numerous occasions. Jim is soon to complete his Ph.D. thesis for a dual degree in creative art and medicine for the research titled "Creative Sparks: The Influences of Epilepsy in Visual art." More than 100 artists with epilepsy, their family members, and artists with migraines participated in this groundbreaking research. The study of the influences of epilepsy in visual art was done in association with the University of Melbourne, St. Vincent's Health, and the Epilepsy Foundation of Victoria. The purposes of the study were to promote a better understanding of epilepsy and associated impacts through the insights represented in the visual expressions and written statements from contemporary artists with epilepsy; to advance a better understanding of the neurological functions of the brain within the creative process, while evaluating if epilepsy can in some ways stimulate and enhance creativity in visual art; and to produce a collection of the visual art of people with epilepsy through an art exhibition and web site. Jim is the founding editor-in-chief and co-designer of a web site titled "Creative Sparks: Visual Art and Epilepsy" at [www.artandepilepsy.com](http://www.artandepilepsy.com). The web site provides a venue for artists around the world to share their visual art and views on how to improve public perception of epilepsy. Jim is also the curator for "Creative Sparks: An Art Exhibition from People with Epilepsy" that opened in May 2009 in Melbourne, Australia. The goal is for the art exhibition to tour internationally in 2011 – 2012 and to be featured along with the research in a film documentary. Jim Chambliss lives in Melbourne, Australia with his lovely wife, Nicola, and their clever two-year old son, Zac. He can be reached by e-mail at [jimchambliss@msn.com](mailto:jimchambliss@msn.com).

### Marion Clignet

Franco-American Marion Clignet (of French parents, born and raised in the USA) discovered at the age of 22 that she had epilepsy and would have to take medication for the rest of her life. A student at the university of Maryland at the time, the medications she was prescribed caused her to sleep through most of her courses. Her driver's license was suspended for one year (until they could sort out the right meds), and there was a whole list of things she should no longer do. That very day she made a promise to herself and those who may suffer from any obstacle in their path that nothing would get in her way when it came to achieving what she set out to achieve, epilepsy or not. After much heated arguing she finally got her neurologist to realize she had a life to lead and it couldn't be done if she slept 19 out of 24 hours a day...so, after loads of trial and error the right medication was found and to replace her lost driver's license she started riding a big green ten speed bike. Years later and with epilepsy in tow she raced to 6 world titles, a world record in the 3kms pursuit, 2 olympic silver medals in the 1996 Atlanta and 2000 Sydney games, and well over 200 career victories. Today, Marion hopes to persuade neurologists to really get to know their patients before making medication choices and she hopes to inspire patients and families on what they can do despite having epilepsy. Living in France, Marion still races with the men locally and has taken up triathlons, marathons, mountain running races and whatever other obstacles she can get herself over. Currently Marion coaches the Bouygues Télécom Professional mens cycling team riding in the Tour de France.

### K C Janardhan

For almost 20 years, K C Janardhan has run Management, Soft Skills Training, Handwriting and Calligraphy and Personality Development workshops and has been regarded as one of the most senior and highly accomplished British & Global Culture Trainers. A connoisseur of handwriting, he is a Questioned Document Examiner (QED) helping various lawyers in cracking forgery cases. Today he is the only person in the world who remains a Connoisseur of Handwriting and Professional Lettering, Calligraphy, Graphology and QED expert, all rolled into one. Founding "The Connoisseur's Quill Inc.," in 1990 to write certificates, citations, invitations and any special writing for corporates, schools, colleges etc, he has written over 60,000 of them for over 200 plus clients across the globe. He is the only Indian to be allowed to write his own passport! Awards and achievements include Rotarian Cultural Ambassador (Group Study Exchange Program) to the UK where he taught power handwriting to students as well as their teachers and Inspectors of Schools at various Schools, Universities and Professional Associations. He is the only Indian to teach "Power Handwriting" to the British. He was the first citizen from Bangalore to be felicitated by Ethos, Swiss Watch Studios under its initiative called "Celebrate Success" in 2007, where after short-listing numerous profiles, Ethos chose him for his steadfast interest and achievements in a field that a few would dare to tread. In 2007, he was also awarded the Extraordinary Achievement Award during the 60th Independence Day celebrations at Raj Bhavan by His Excellency Shri T.N.Chaturvedi, Governor of Karnataka and the Outstanding Person with Epilepsy Award by the IBE. A talented artist, K C Janardhan chose calligraphy for its emphasis on precision and beauty and to demonstrate that people with epilepsy can be creative, systematic and organized achievers with excellence and lead a respectful, meaningful, eventful and satisfying life, and to disprove the myths about people with epilepsy.

### Simon Jones

Dr Simon Jones is a consultant psychiatrist at the Royal Melbourne Hospital/NorthWestern Mental Health and is Academic Fellow in the Department of Psychiatry, University of Melbourne. As a psychiatry trainee he worked in neuropsychiatry and as an epilepsy fellow. He continues to have an interest in neuropsychiatric aspects of epilepsy and psychogenic seizures and sees patients with epilepsy in private practice.

## **Wally Lewis**

Wally Lewis is generally considered one of the greatest Rugby League players of all time. Nicknamed The King, he represented Queensland in 31 games from 1980 to 1991 and was captain from 1981 to 1991. He was named Man of the Match in 8 State of Origin games. He also represented Australia in 33 international matches from 1981 to 1991 and was national team captain from 1984 to 1989. A statue was raised in his honour at the Brisbane Suncorp Stadium. On his retirement from professional football, Wally works as a commentator and sport presenter for Channel Nine. But Wally had a secret and when he had an epileptic seizure live on air in November 2006, his world came crashing down. The medical condition he'd spent two decades attempting to conceal from the public was now exposed. With his health on a downward spiral, the only solution was the one that terrified him the most — brain surgery. In his autobiography *Out of the Shadows - A champion's return to the spotlight*, Wally candidly speaks about his retirement from rugby league — from the darkest days of depression and debilitating seizures to his hard-fought recovery and triumphant return to the nation's TV screens.

## **M M Mehndiratta**

Dr M M Mehndiratta's professional experience spans some 30 years, and teaching experience, 28 years. He is a member of the Royal College of Physicians-London, Royal College of Physicians & Surgeons Glasgow (FRCPSG), Royal College of Physicians (Edinburgh) United Kingdom, and the Fellow Cochrane Neuromuscular Group, United Kingdom. Dr Mehndiratta was a recipient of WHO fellowship in Critical Care Neurology. He has published 150 scientific papers in international & national journals, contributed some 50 chapters in various books, and has edited 6 books. Currently Dr Mehndiratta occupies the following positions: Secretary General-Indian Epilepsy Association, Vice Chair-South East Asia region IBE, Member-Secretary-IEC MAMC, Chair-Public Action Advocacy Task Force World Federation of Neurology and Secretary-Asian Oceanian Association of Neurology. Dr Mehndiratta's work has been recognised internationally with numerous awards including: A.B.Baker Teacher Recognition Award of American Academy April 2008, Ambassador of Epilepsy Award July 2007, Donald M. Palatucci Advocacy Advisor (2009) and Advocate (2008) of American Academy of Neurology; and nationally, being honoured with the Netaji Oration Award, Pawan Kumari Jain Oration, Prestigious Delhi State Award and the Late Pt. Radha Kishen Memorial Award.

## **Rosemary Panelli**

Dr Rosey Panelli has worked with the Epilepsy Foundation of Victoria since 1995. She has a particular interest in the communication of health information and community participation in health services. She has a Diploma of Volunteer Management and a Master of Public Health. This year she completed her PhD after carrying out a prospective psychosocial study of patients presenting to First Seizure Clinics. Nested within that research was a randomized controlled study evaluating the effect of a peer support.

SUDEP has been a target of action in Australia for more than 10 years and Dr Panelli has been involved in that work from the beginning. Having formed early links with Epilepsy Bereaved UK, she has worked to raise awareness of SUDEP and to encourage support for those affected. She initiated memorial services in Melbourne and encouraged health professionals, including pathologists, to work together on the issue. She served on the IBE Commission for Risk and Insurability and in 2005 she co-edited a resource booklet, SUDEP; a global conversation, which was produced jointly with Epilepsy Bereaved. In 2008 she was invited to participate in a SUDEP workshop at the National Institute of Neurological Disorders and Stroke, Washington and has continued to participate in the ongoing education workgroup. Dr Panelli recently collaborated with Jane Hanna of Epilepsy Bereaved to write a chapter titled *Challenges in overcoming ethical, legal and communication barriers in SUDEP*, for a forthcoming publication in the US. She is currently working as the practice manager for a general practice in country Victoria and as a researcher for a regional community health service. She is a member of the research task force of the International Bureau for Epilepsy, and the task force for reducing epilepsy deaths which has been initiated by the Epilepsy Foundation of Victoria.

## **Wayne Pfeiffer**

Wayne Pfeiffer joined the Epilepsy Foundation of Victoria in January 2009 as General Manager Client Services and has more than 20 years of experience in a range of community service organisations in health promotion, community development, adult education, problem gambling and disability settings, both in Australia and in Ireland. In 2007 he was awarded a Victorian Department of Human Services Ethel Temby study tour to Europe focusing on individualised funding. His qualifications include B Ed. (Secondary), Grad Dip. Comm Ed., Grad Cert. Professional Management.

## **Jennifer Preston**

An education consultant and specialist tutor, Jennifer was educated in the UK and the Sorbonne, Paris. Married to naval historian Antony Preston (died 2004), they had four children: Matthew, William, Katie and Eleanor. William had his first seizure at 17 and died from SUDEP in 1988, aged 22 years. Jennifer is a founder member and trustee of Epilepsy Bereaved, registered as a charity in 1995, and has worked closely with the Epilepsy Foundation of Victoria and Epilepsy Australia since 1997. Jennifer lives in Fulham, London.

## **Mike Salzberg**

Dr Mike Salzberg is director of consultation-liaison psychiatry at St Vincent's Hospital and A/Prof in the University of Melbourne Dept of Psychiatry. His interests are in the psychological problems of physically ill patients in hospital. He has worked with epilepsy patients for some years and is involved in research on the links between stress and epilepsy.

## **Graham Scambler**

Graham Scambler is Professor of Medical Sociology and Director of the Centre for Sociological Theory and Research at University College London. He has taught medical students and doctors for over thirty years and is editor of the textbook 'Sociology as Applied to Medicine', now in its sixth edition. He began his academic career researching into epilepsy and has written extensively on the sociology of chronic and disabling conditions and on stigma. He is co-editor of the international journal 'Social Theory and Health', and has published over 100 books, chapters and peer-reviewed papers.

## **Elson So**

Professor of Neurology and Director of Electroencephalography at the Mayo Clinic College of Medicine, Dr. So serves on the editorial boards of the journals *Epilepsia*, *Epilepsy Research*, and *Journal of Clinical Neurophysiology*. He is also a member of the Board of Directors of the American Epilepsy Society (AES), and the Council of the American Clinical Neurophysiology Society. Dr. So also serves on the Professional Advisory Board of the Epilepsy Foundation of Minnesota. He is a member of the Governance Committee and Conflict of Interest Committee of the AES Board of Directors. He has also served on the Professional Advisory Board of the Epilepsy Foundation of America. He is the past chair of the Section of Clinical Neurophysiology of the American Academy of Neurology. Dr. So has directed educational courses, symposiums, and plenary sessions at the American Academy of Neurology, American Epilepsy Society, the American Clinical Neurophysiology Society, and the Organization for Human Brain Mapping. He chaired the Joint AES-EF SUDEP Task Force, and the National Institute of Neurological Disorders and Stroke (NINDS) Workshop on SUDEP. His research interests are in advanced SPECT imaging, SUDEP, and the natural history, treatment outcomes and electroclinical aspects of intractable epilepsy.

## **Ernest Somerville**

Ernest Somerville is Director of the Comprehensive Epilepsy Service of the Prince of Wales Hospital in Sydney and Associate Professor at the University of New South Wales. Ernie studied medicine at Sydney University and received his training in neurology and epilepsy at Duke University, North Carolina, USA. He established the epilepsy surgery program at Westmead Hospital in Sydney and became head of the Prince of Wales program in 2003. He has been an investigator on numerous AED clinical trials. He co-directs the Australian and New Zealand Association of Neurologists Annual Course in Clinical EEG. He has lectured extensively in Australia and Asia. Research interests include clinical epilepsy, EEG, epilepsy in developing countries and seizure aggravation by anti-epileptic drugs. He established the East Timor National Epilepsy Training Program, which trains Timorese health workers to diagnose and manage epilepsy and performs community education. Ernie is a Past President of the Epilepsy Society of Australia and chairs its Driving Committee. In 2009, he received an Ambassador for Epilepsy Award from the International League Against Epilepsy.

## **Grace Tan**

Grace Tan has been involved with the Singapore Epilepsy Foundation since 2000 – first as Secretary and then elected as Chairman since 2006. Her interest and involvement in epilepsy grew stronger as she learnt more about this condition and working with people and children with epilepsy and their careers. Her personal commitment is to promote greater awareness of epilepsy amongst employers so as to eradicate the misconceptions of epilepsy and to enhance employability for people living with epilepsy. Grace's professional background is a chartered secretary and is the CEO of the The Singapore Association of the Institute of the Chartered Secretaries and Administrators. In 2009, Grace was elected Treasurer of the International Bureau for Epilepsy.

## **David Weintrob**

Dr David Weintrob is currently employed as Senior Clinical Neuropsychologist in the Department of Neuropsychology at Austin Health, Melbourne, Australia. He completed a Ph.D at The University of Melbourne in 2005, having been admitted to the degree of Master of Science (Clinical Neuropsychology) at the same institution in 1997. For the last 12 years Dr Weintrob has provided neuropsychological services to the Comprehensive Epilepsy Program at Austin Health. His doctoral thesis explored the neural basis of memory dysfunction in temporal lobe epilepsy and neuropsychological dysfunction in epilepsy remains a principle research interest of his.

## **Sarah Wilson**

Sarah Wilson is an Associate Professor & Reader in Psychological Sciences at The University of Melbourne, and the Director of Neuropsychological Research in the Comprehensive Epilepsy Program at the Austin hospital. She is also an Adjunct Senior Fellow in the Department of Medicine at The University of Melbourne, and a Research Fellow at the Florey Neuroscience Institutes. As Director of Neuropsychological Research, she has established a psychosocial rehabilitation service and outpatient clinic for patients and families treated within the Comprehensive Epilepsy Program at Austin Health. She has also led a successful psychosocial research program that has been awarded 3 international prizes and 1 national prize. She is currently contributing to the ILAE Psychobiology Subcommittee for the Treatment of Neuropsychiatric Conditions Associated with Epilepsy, and is a member of the Editorial Board of the journal *Epilepsy & Behavior*.

## **Beverley Vollenhoven**

Associate Professor Beverley Vollenhoven is the head of Gynaecology at Southern Health. She subspecializes in the field of Reproductive Endocrinology and Infertility. She is the head of the Contraceptive Counselling Clinic and a Consultant Gynaecologist in the Menopause Clinic at the Monash Medical Centre. She is a clinician at Monash IVF. Her major basic research interests are in the growth and development of uterine fibroids and her clinical research interests include infertility, ovulatory disorders and their treatment and menopause.