

*International*

# *Epilepsy News*

Newsletter of the

International Bureau for Epilepsy Issue 3 - 2008



**Report from Marseille**

**ELECTIONS 2009**

***Working with the Media***

# The President's Message



Dear Friends

2008 has been a very busy and interesting year for IBE, with many new activities underway, as well as the regional congresses that have taken place in Xiamen, Marseille and Montevideo.

At the end of October I returned home from the very successful 11<sup>th</sup> European Conference on Epilepsy & Society that took place in Marseille and which attracted more than 300 delegates from 51 countries, both from within Europe and from as far a-field as Australia!

The main topic "Active Life and Epilepsy – Achieving Goals with an Active Life" included discussion on legislative issues and the UN Disability Convention, contemporary literature, family, working with the media, just to mention a few. A key message was also the role that humour plays in epilepsy, which was mirrored by the stories of life experience provided by the session speakers. IBE would like to thank the members of the organising committee, chaired by Peter Dahlqvist, for their hard work over the past 2 years in creating a great conference with a very interesting programme. Thanks are also due to Jacqueline Beaussart and the members of AISPACE, IBE's Full Member in France, for their help and assistance.

The 5th Latin American Epilepsy Congress took place in Montevideo at the beginning of November. This was a congress I was very much looking forward to attending but, unfortunately, a resilient virus prevented me from travelling. I was delighted to learn that Montevideo was another great congress, with delegate numbers reaching almost 700! I am grateful to Lilia Núñez, Elza Marcia Yacubian, Tomás Mesa and Carlos Acevedo, who prepared the special programme for people with epilepsy and their carers, as part of the congress programme.

As year draws to a close it is time to look forward to 2009, which will be a very important time for IBE as we prepare for the congress in Budapest and get ready for the changeover of the International Executive Committee and the Regional Executive Committees that will take place at the General Assembly.

Until next time - best wishes to all!

Susanne Lund  
President

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The International Bureau for Epilepsy, with membership of 118 epilepsy associations based in 92 countries worldwide, works to improve the quality of life for all people affected by epilepsy.

# The Editor's Letter



Dear Friends

In the Southern Hemisphere we are enjoying late spring after a rainy winter, so nature is starting another cycle (including hay fever and the sore eyes and sneezing that it brings). This issue of IE News includes several interesting reports. We can mention an important workshop that took place in Honduras. This is an initiative within the framework of the

Global Campaign Against Epilepsy and again reinforces the importance of work together with our partners, the WHO and ILAE.

You are going to be delighted with a real masterpiece prepared by our Past President Philip Lee in an article that focuses on working with the media. It is of maximum importance to have guidance about how to use the opportunity of getting access to the media and the best form of doing that in order that our message is positive and clear.

We include news about the elections of the International Executive Committee for the term 2009-2013 and the list of those nominated. In addition, there are reports from our recent Regional Congresses in Montevideo and Marseille; news from EPI-CURE; as well as important news articles sent by our Members around the world, including the US, Australia, UK and India.

Finally we have news of the activities of our President Susanne Lund, and of course her President's column.

So, as always, the magazine is full of interesting reports and articles - and I hope that you will enjoy reading it.

Kind regards

Carlos Acevedo  
Editor

## International Epilepsy News on the Web

IE News is now available on the IBE website

[www.ibe-epilepsy.org](http://www.ibe-epilepsy.org)

Previous issues can be found under the tab **IE News**, while the current issue is available to IBE Members on the **Members** section.

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Rick O'Shea, a presenter on Irish national radio, spoke in Marseille about the humorous side of having epilepsy. Enjoy more photos from the conference on page 14.

Photo: Eoghan Megannety

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# IBE/ILAE/WHO Global Campaign Against Epilepsy 'Out of the Shadows'



Susanne Lund, President of IBE, met with Dr Ali Alwan, Assistant Director General of the World Health Organisation at the WHO headquarters in Geneva, Switzerland on 9 September. Also present at the meeting were Professor Peter Wolf, President of ILAE; Professor Giuliano Avanzini and Philip Lee, the co-Chairs of the Global Campaign against Epilepsy and Hanneke de Boer. Attending the

## Assistant Director General of the WHO meets with IBE President

Susanne Lund travels to Geneva to meet Dr Ali Alwan

meeting from WHO, in addition to Dr Alwan, was Dr Tarun Dua, a technical officer working on the Global Campaign and Dr Benedetto Saraceno, head of the department of mental health and substance abuse.

Dr Alwan was appointed to his position earlier this year and the meeting was arranged to introduce him to the Global Campaign, to update him about past achievements and to tell him about current activities. The meeting also provided the opportunity for Susanne Lund to outline the future of the Campaign and for IBE, ILAE and WHO to all reaffirm their commitment to the partnership of the Global Campaign.

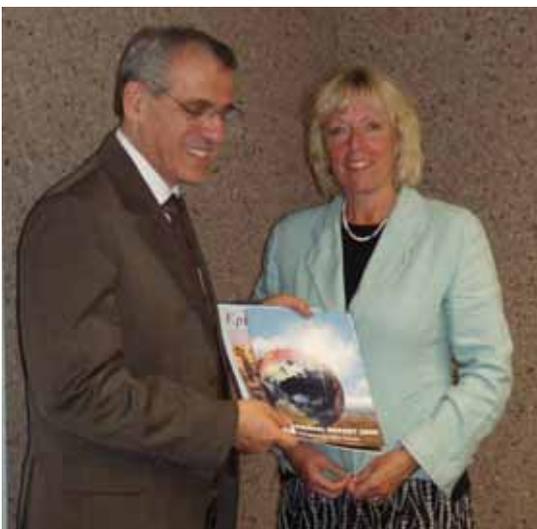
Dr Alwan acknowledged the tremendous efforts of the Campaign so far and looked forward to celebrating more success and achievement with IBE and ILAE in the future. He stated that the challenges in the management of epilepsy, concerning prevention, education and stigma should be addressed through the Global Campaign partnership and the lessons learned from the demonstration projects now needed to be translated into

wider practical action to spread their benefit to as many people as possible.

Susanne Lund emphasised the importance and value of strong collaboration between IBE, ILAE and WHO at a regional level. She also commented that IBE feels that it is of the utmost importance to convince politicians to provide at least a minimum standard of care for people with epilepsy.

### Photographs:

- Colourful shutters in the Old Town of Geneva (photo Susanne Lund)
- Dr Alwan is presented with a copy of the IBE Annual Report by Susanne Lund
- From left to right: Dr Benedetto Saraceno, Mrs Susanne Lund, Professor Peter Wolf and Dr Ali Alwan





## Reporte sobre meeting OMS/OPS en Honduras

Carlos Acevedo, Vice-Presidente Latinoamérica

En la capital de Honduras Tegucigalpa se realizó entre el 20 y el 22 de Agosto del año 2008 el Taller Sub-Regional: Situación actual de la Epilepsia en Latinoamérica y el Caribe, Desafíos y Perspectivas.

### Participantes:

- Dr José Bertolote en representación de la Dra Tarun Dua por OMS
- Dr Jorge Rodríguez, Coordinador del Proyecto de Salud Mental, Discapacidad y Rehabilitación OPS/OMS
- Dr Víctor Aparicio, OPS/OMS Panamá
- Raquel Fernández, Profesional Nacional OPS/OMS Honduras
- Dr Carlos Acevedo, Buró Internacional para la Epilepsia (IBE)
- Juana Rosario Mejía de Rodríguez, Asesora Subregional de Medicamentos, Vacunas y Tecnologías de la Salud OPS/Guatemala
- Dr Marco Tulio Medina, Presidente de la Comisión Latinoamericana de la Epilepsia de la Liga Internacional contra la Epilepsia
- Reinaldo Moncada, psiquiatra
- 13 profesionales neurólogos, psiquiatras, psicólogos y otros propuestos por la Secretaria de Salud y OPS/Honduras y 7 expertos de Guatemala, El Salvador, Costa Rica, Panamá, Cuba, República Dominicana y México.

El objetivo general fue de contribuir al mejoramiento de la atención de los pacientes con epilepsia, mediante la identificación de necesidades, el establecimiento de prioridades y estrategias, así como el desarrollo de planes y servicios en Centro América y El Caribe Hispano.

### Objetivos específicos:

- Presentación del informe Regional sobre la Epilepsia: Dr Carlos Acevedo.
- Presentación del libro 'Trastornos Neurológicos, Desafíos para la Salud Pública': Dr José Bertolote.
- Evaluar a nivel subregional las necesidades prioridades y estrategias para mejorar la atención a las personas que padecen de epilepsia.
- Presentar y discutir los avances y experiencias en los planes y servicios dedicados a la atención de la epilepsia en los países Centroamericanos y del Caribe Hispano.
- Proyectar las líneas de cooperación técnica de la OPS/OMS en este campo para el 2008-2009.

Durante los primeros 2 días se presentaron ponencias sobre los principales problemas de la región y en particular cada país participante dio cuenta de sus realidades.

Además se incluyeron tópicos como son: situación actual de los Servicios de Salud Mental en Centroamérica; experiencia OMS en Proyectos Demostrativos (PD); neurocisticercosis y epilepsia; acceso a los antiepilepticos; medios diagnósticos en las epilepsias; programa de Post Grado en Neurología en CA & EC; cirugía de la Epilepsia en CA & EC; aspectos de fisiología del sistema nervioso central y las epilepsias y centros de atención de alta complejidad en epilepsia.

En el tercer día del taller se formaron 2 grupos con 2 objetivos diferentes:

- Proyecto de Demostración en Honduras, dirigido por el Dr Marco



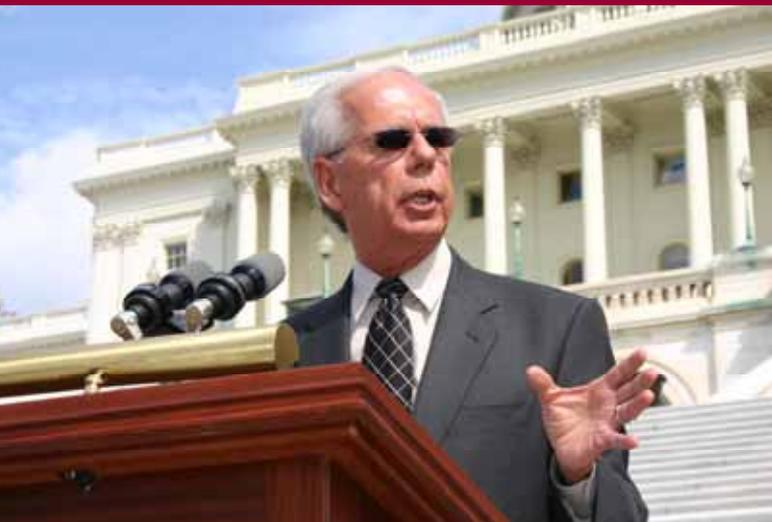
*Dr Carlos Acevedo, Dr Marco Tulio Medina, Dr Jorge Rodríguez, Dr Victor Aparicio, Dr José Bertolote.*

Tulio Medina. Se inició la elaboración de un proyecto basada en las experiencias previas en PD, particularmente del exitoso PD realizado en Brasil entre los años 2002 y 2006. Se redactó un primer borrador del proyecto incluyendo la participación de las autoridades Gubernamentales de Salud de Honduras y se intentará comenzar que el próximo año en una localidad suburbana de Honduras.

- Iniciativa Regional para crear planes y desarrollar iniciativas para mejorar la atención de la epilepsia en CA & EC considerando las realidades de los distintos países en cuanto a desarrollo económico y social, geografía, recursos humanos y técnicos. La idea subyacente es llegar a un universo de pacientes estimado en un 60% de las personas con epilepsia en CA & EC que no han sido diagnosticados o que no están siendo tratados adecuadamente.

Este Taller se desarrolló en un marco de gran camaradería, grata convivencia y reuniones de trabajo muy interactivas. Finalmente es necesario destacar que este Taller le otorga nuevos bríos a la Campaña Global "Sacando a la Epilepsia de las Sombras" con este renovado protagonismo de OMS/OPS, quien además le dio el apoyo económico para iniciar esta iniciativa.

# US Congress Restores the Promise of the Americans with Disabilities Act



“For those of us with epilepsy, this legislation is even more important than the passage of the original ADA. This bill was primarily focused on correcting our exclusion from the original Americans with Disabilities Act by misguided court decisions.

Congress listened to us and we thank them”

Tony Coelho  
former US congressman and immediate past board chair of the Epilepsy Foundation, a primary author of the original Americans with Disabilities Act.

Epilepsy Foundation of America, together with other US organisations working on behalf of persons with disabilities, celebrated a momentous occasion on 25th September, when President Bush signed the ADA Act of 2008 into law. In a private signing ceremony, the US President secured protection against discrimination in the workplace for every American with a disability.

The bill marked a historic move towards securing the promise of the original Americans with Disabilities Act (ADA), which, by coincidence, had been signed into law by his father President George HW Bush in 1990. Former President Bush was also present at the signing ceremony in Washington.

Speaking at the ceremony Tony Coelho, immediate past chair of the Epilepsy Foundation Board of Directors and a former congressman from California said:

“For those of us with epilepsy, this legislation is even more important than the passage of the original ADA. This bill primarily focussed on correcting our exclusion from the ADA by misguided court decisions. Congress listened to us and we thank them.”

The ADA opened many doors for Americans with epilepsy or other disabilities. It changed the country’s expectations and opinions of people with disabilities, setting a positive

standard for other countries around the world. However, US Supreme Court decisions over the past 10 years narrowed the definition of disability, leaving thousands of Americans, including those with epilepsy, without civil rights protection in the workplace. The new law will overturn several of those decisions so that people with disabilities, including people with epilepsy, will again be protected by the Act.

Epilepsy Foundation joined hundreds of employer, disability, civil rights and other organisations in a strong collaboration that resulted in the introduction of the new law. Representatives of the board-based alliance gathered following the historic signing to applaud the new law.

Eric Hargis, Epilepsy Foundation President and CEO stated that:

*“Now future generations of people with epilepsy will not have to prove they’re disabled if they’re discriminated against in the workplace, educational institutions or any other venue”.*

Elizabeth Goldberg, who has epilepsy and is the founder of the Epilepsy Foundation’s youth council said:

*“This means a lot. I am 24 years old—I have a while life of work ahead of me”.*

## Text from original ADA

An individual with a disability is a person who:

- Has a physical or mental impairment that substantially limits one or more major life activities;
- Has a record of such an impairment; or
- Is regarded as having such an impairment.

A qualified employee or applicant with a disability is an individual who, with or without reasonable accommodation, can perform the essential functions of the job in question. Reasonable accommodation may include, but is not limited to:

- Making existing facilities used by employees readily accessible to and usable by persons with disabilities.
- Job restructuring, modifying work schedules, reassignment to a vacant position;
- Acquiring or modifying equipment or devices, adjusting or modifying examinations, training materials, or policies, and providing qualified readers or interpreters.

An employer is required to make a reasonable accommodation to the known disability of a qualified applicant or employee if it would not impose an “undue hardship” on the operation of the employer’s business. Reasonable accommodations are adjustments or modifications provided by an employer to enable people with disabilities to enjoy equal employment opportunities.

**E**pilepsy Awareness Program has been a major focus for The Epilepsy Centre. The aim is to provide services for people with epilepsy, their families and the community throughout regional South Australia and The Northern Territory.

The State of South Australia covers an area of over 1 million square kilometres, so as you can imagine many miles have been covered along highways and unsealed dusty roads since the program began. A reliable vehicle is essential and the Epilepsy Centre was delighted when Community Benefit SA funded the purchase of a vehicle to handle difficult conditions. Many rural and remote areas have been visited and assistance has been provided to indigenous communities, school communities, rural support groups, nursing and medical staff, libraries, and workplaces. The program provides communities with a comprehensive range of services:

general epilepsy education, teacher training, medical staff training, formulating care plans, referring clients to health and welfare agencies, counselling, advocacy and support.

The results are tangible. There is now greater awareness and knowledge about epilepsy and the provision of new services for people living with epilepsy in remote locations has had a marked effect on their self esteem and confidence. The Epilepsy Centre has also seen an improvement in the health of people living with epilepsy in these communities.

The program has gone a long way to demystify epilepsy, particularly in indigenous communities. Similarly, the expanded service is well regarded by regional medical providers as the provision of current information on epilepsy, seizure recognition and medications has greatly increased their epilepsy knowledge.

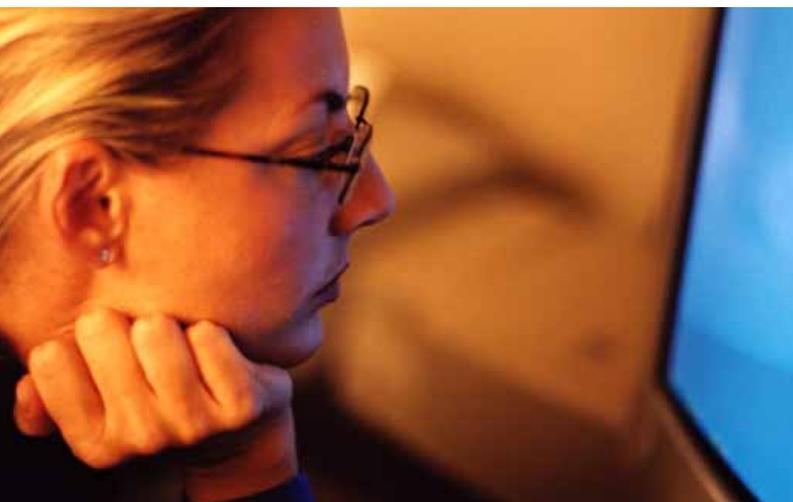
In the Northern Territory, an area even larger than the State of South Australia, we have begun to mirror the services offered in rural and remote South Australia. We have established relationships with a number of Aboriginal Health Centres and partnered with other Disability and Health Support Agencies to deliver services collaboratively throughout the Northern Territory.

We are about to embark on a new exciting project to connect people in rural and remote areas to the Epilepsy Centre via Video Link up. We plan to pilot the project in Mt Gambier in the South East of South Australia. This project will enable support groups to have access to our facilitators via video link as well as enabling our workshops to be streamed live, giving participants in rural areas the ability to interact with the speakers and other participants.



Providing services to a region covering 2.5 million square kilometres seems unimaginable. But not for Mark Francis, Services Manager for The Epilepsy Centre of South Australia and The Northern Territory. Because this vast tract of country is his 'office' and the isolated communities he assists are his 'clients'.

## in the Australian Outback



## Research on Cognition in Epilepsy

SallyAnn Wakeford, a PhD student at the University of Bath, UK would like to hear from adults with epilepsy willing to complete a questionnaire that investigates how epilepsy affects the way we think and the way we behave.

The purpose of SallyAnn's research is to develop a specific way of measuring cognitive and behavioural abilities, which are important to epilepsy. The research aims to raise awareness that people with epilepsy need special consideration with psychological testing, since present tests are not designed especially for people with epilepsy and may not be accurate.

Improved tests will benefit all people with epilepsy, whose abilities will be measured in a more accurate way. It will reduce the chances of a misdiagnosis, and it is hoped that this will improve which treatments are offered to people with epilepsy.

The questionnaire takes about 15 minutes and can be done online. If you would like further information or to get a link to the research web link, you can contact Sallyann at [srw@bath.co.uk](mailto:srw@bath.co.uk).



# IBE Elections 2009

Full Members nominate candidates to stand for election to the International Executive Committee 2009—2013

The call for nominations for candidates to stand for election to the positions of IBE President, Secretary General, Treasurer and Vice Presidents came to a close in early October.

Since then the Election Task Force has invited candidates to submit their election statements and these statements, along

with ballot forms and guidance notes, were circulated to Full Members on 1st November. All papers are also available on the Election section of the website.

Full Members may vote for the candidates of their choice until early January 2009 and it is expected that the results will be announced by mid-January.

## Candidates for President



### Mr Mike Glynn, Ireland

Mr Glynn is the current Treasurer of IBE. He is also Chair of the Task Force on Driving and a Member of the Management and Political Action groups of EUCARE.

Before his election as IBE Treasurer, he looked after IBE's finances on a voluntary basis for several years as Finance Manager. He is Chief Executive of Brainwave The Irish Epilepsy Association in Ireland.



### Dr Thanos Covanis, Greece

Dr Covanis is currently Vice President Europe and Vice Chair of the European Regional Executive Committee. He chairs the IBE Commission for the Regions and is a Member of the Management and Political Action

groups of EUCARE.

A paediatric neurologist, he is President of the Greek Bureau for Epilepsy and Greek League Against Epilepsy.

## Candidates for Treasurer



### Dr MM Mehndiratta, India

Dr Mehndiratta was Secretary General of the Asian Oceanian Epilepsy Association from 2000 to 2004 and Chairman of the Asian Oceanian Epilepsy Society from 2004 to 2007.

He has been a member of the Governing Council of the Indian Epilepsy Association for the last ten years and Treasurer of the Indian Epilepsy Society for six years. He is a Professor of Neurology.



### Mrs Grace Tan, Singapore

Mrs Tan is Chairman of Singapore Epilepsy Foundation.

She is Chief Executive of Singapore Association of Chartered Secretaries and Administrators; Director of the Centre for Corporate Management &

Development; Vice Chairman, Taxpayers Feedback Panel, Inland Revenue Authority of Singapore; and Board Member, School of Business Management, Jimei University.

## Candidate for Sec. General



### Mr Eric R. Hargis, USA

Mr Hargis is the President and Chief Executive Officer of the Epilepsy Foundation and has served the epilepsy community in the United States since 1998.

He joined the IBE Executive Committee in 2001 as Vice President North American Region. He was subsequently elected Secretary General. Two years ago he introduced the Promising Strategies Program.

## Immediate Past President



### Mrs Susanne Lund, Sweden

The election of the President, Secretary General and Treasurer will be decided by a ballot of all Full Members. In each election the delegate receiving the most votes will be deemed to be elected.

Full Members are also being invited to ratify the appointment of the current President, Susanne Lund, as IBE Immediate Past President for the term 2009-2013.

Ballot Paper  
International Executive  
Committee 2009-2013

## Election Schedule

### International Executive Committee

**1st November:** Circulation of ballot papers

**2nd January 2009:** Balloting ends; results announced shortly after.

### Regional Executive Committees

**Early February:** Call for nominations.

**Early March:** Close of nomination period.

**Early April:** Ballot papers will be circulated.

**Early June:** End of balloting period and results shortly thereafter.

## Election of Regional Vice Presidents



The election of each regional Vice President will be decided by a ballot of all Full Members from within the region in which the candidate is standing. In the case of an election in which there is more than one candidate nominated, the delegate receiving the most votes will be deemed to be elected.

### Africa



#### Mr Anthony Zimba, Zambia

Mr Zimba is an epilepsy specialist in the Ministry of Health; National Chairman of Epilepsy Association of Zambia; Secretary IBE Africa Region Committee and Board Member of Directors at the Secretariat of Africa Decade of Persons with Disabilities.

He founded Epilepsy Association of Zambia 2001 which has now 500 registered members.

### Eastern Mediterranean



#### Dr Abdulaziz Al Semari, Saudi Arabia

Currently Vice President Eastern Mediterranean Region, Dr Abdulaziz is a Neurologist at King Faisal Specialist Hospital in Riyadh where he is Director of the Comprehensive Epilepsy Program and Section Head of Neurology.

Dr Abdulaziz established the Epilepsy Support & Information Centre (IBE Full Member) and the Epilepsy Registry.

### Europe



#### Dr Janet Mifsud, Europe

A pharmacologist with special interest in antiepileptic drugs, Dr Mifsud helped set up Caritas Malta Epilepsy Association, IBE's Full Member.

Dr Mifsud is experienced in accessing and lobbying for EU funds. She is also an expert evaluator for FP7 research projects, a committee member on the European Medicines Agency and Secretary of EUREPA, European Epilepsy Academy.

### Latin America



#### Dr Carlos Acevedo, Chile

Dr Acevedo is currently IBE Vice President Latin America and Editor of International Epilepsy News.

Dr Acevedo is a member of Anliche, the IBE Full Member in Chile and is involved in the Chilean Drugs Bank project. He edited the first Spanish epilepsy book for people with epilepsy and is involved in creating an action plan for the Global Campaign in the PAHO region.



# IBE Elections 2009

Election of Regional Vice Presidents  
*continued from previous page*

## North America



### Mrs Mary Secco, Canada

Mrs Secco joined the International Executive Committee at the end of 2007, as IBE Vice President North America.

Mrs Secco has been Executive Director of the Epilepsy Support Centre, a community based epilepsy centre in London, Canada. In this role, she works in providing counseling, information and support to persons living with epilepsy.

## South East Asia



### Dr Vinod Saxena, India

Dr Saxena is a clinical pharmacologist with experience in antiepileptic and psychoactive drug research, medical education, administration and medico-social work in epilepsy.

He is a founder member of the Indian Epilepsy Association and the Indian Epilepsy Society and has served on the boards of both associations in various officer positions since 1992.

## Candidates for Western Pacific



### Mr Frank Gouveia, New Zealand

Mr Gouveia is Senior Executive Officer of Epilepsy Association of New Zealand. Prior to his current position working with an NGO, he was involved in the business arena both in senior management positions and as a

business owner specialising in international negotiations. He has found the greatest satisfaction in working in the community and volunteer sector.

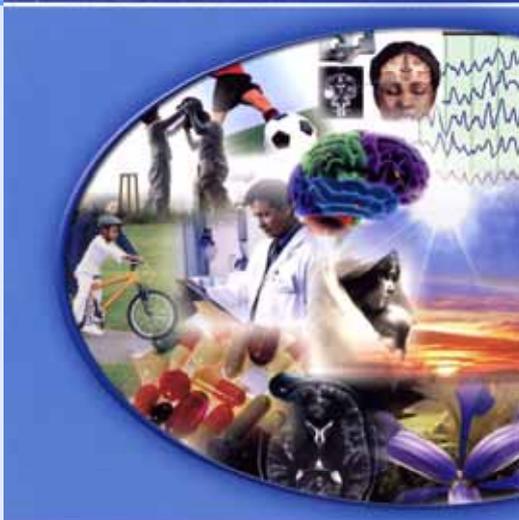


### Dr Shunglon Lai, Taiwan

Dr Lai is chief of the epilepsy section in the Department of Neurology, Kaohsiung Chang-Gung Memorial Hospital, Taiwan and is IBE Vice President Western-Pacific region.

In his spare time, since 1998, he has been organising the epilepsy self-help group in Kaohsiung and works with the Taiwan Epilepsy Association to promote the quality of life for people with epilepsy.

INDIAN EPILEPSY SOCIETY  
Guidelines for the  
Management of Epilepsy  
in India



INDIAN EPILEPSY ASSOCIATION-  
18th INTERNATIONAL EPILEPSY CONGRESS TRUST

## Tackling the Epilepsy Treatment Gap in India

With a population of more than one billion, it is estimated that India accounts for 10-20% of the global burden of epilepsy, according to the foreword written by Prof Gourie-Devi and Dr VS Saxena for this latest publication of the Indian Epilepsy Society.

With just one neurologist for every 1.25 million people in India, and with training in the diagnosis and treatment of epilepsy not included in the syllabus of medical undergraduates, it is not surprising that

the treatment gap is estimated to be between 38 and 80%.

Recognising the need for urgent action, the Indian Epilepsy Society, led by Dr Satish Jain, took the lead to develop guidelines for the management of epilepsy in India (GEMIND). Work on the guidelines involved a Core Committee and a group of peer reviewers. It is hoped that GPs will use GEMIND in their clinical practices to diagnose and provide treatment for people with epilepsy.

Guidelines for the Management of Epilepsy in India was funded by the Indian Epilepsy Association - 18th International Epilepsy Congress Trust

# Rachel: A Perfect Life



Rachel is an Australian single mother, a resilient young woman who has faced many problems in her life. Now she wants brain surgery to rid her of the epilepsy that is ruling her life. This intimate observational documentary follows Rachel through the surgery assessment process, the subsequent brain surgery, her reunion with her children, and the twists and turns along the way. There are interviews with eminent neurosurgeons, including Prof Sam Berkovic and Prof Gavin Fabinyi, Austin Hospital.

This award-winning feature-length documentary gives an insight into epilepsy through Rachel, who

bravely agreed to participate in the documentary, laying bare her life and also discussing her abusive past. She hasn't been able to keep a job for many years because of her epilepsy and constant seizures. She feels her life is out of control and by choosing to have brain surgery she believes she will have the chance to find a new life, a perfect life. The 90-minute documentary has won several TV and film festival awards.

*"A courageous journey of determination and hope told with disarming candour—truly inspirational"* says Denise Chapman of Epilepsy Australia.

*Further details from Front Row Video Distribution at [frontrowvideo@frontrowvideo.com.au](mailto:frontrowvideo@frontrowvideo.com.au).*



## International League Against Epilepsy 1909 to 2009: *A Centenary History*

S. Shorvon, G. Avanzini, J. Engel, H. Meinardi,  
S Moshe, E. Reynolds, G. Weiss, P. Wolf

Founded on August 30th 1909 in Budapest, the International League Against Epilepsy (ILAE) is the earliest neurological society still in existence. To mark its centenary in 2009, the League will produce a presentation volume of its history. Diligently researched, this book uses personal testimonials, published reports, the ILAE archives and research developments to provide a unique and detailed social and scientific history.

The book will chart in detail the course of the ILAE and of epilepsy from 1909 to 2009. Much of the ma-

terial comes from private sources and archives and has never before been published.

The publication will be over 300 pages in length, fully illustrated with historical pictures and photographs. Each copy will be lavishly produced, beautifully presented, and individually numbered and named. It will be a valuable volume for the library of every epileptologist and bibliophile.

The book is being published in a limited edition of 1000 copies. To ensure that all individuals have the opportunity to own a copy, the ILAE is offer-

ing the book at a reduced price of £49 / \$99 / Euro 65 to those reserving a copy in advance. These copies will include an individual presentation bookplate and individual number.

### Reserve your copy

To reserve a copy, send your name, email or fax number and address for invoice to Prof Simon Shorvon at [epilepsypa@ion.ucl.ac.uk](mailto:epilepsypa@ion.ucl.ac.uk) or by mail to:

Prof Simon Shorvon, Box 5, National Hospital for Neurology and Neurosurgery, London WC1N 3BG, UK.



## Getting your message across

*Philip Lee, Chief Executive, Epilepsy Action and IBE Immediate Past President, writes about effective techniques to adopt when working with the media*

In a world where epilepsy is still seemingly universally misunderstood it is crucial that inappropriate attitudes to the condition are challenged and that people receive accurate information.

Raising awareness and educating people are critical for the removal of stigma. Fundamental to achieving this goal is using the press media - national and local television and radio,

national and local newspapers and magazines and websites.

Appearing in the media gives you a direct line to your audience. It gives your organisation and your message authority and credibility, raising your profile and your status. Of course that's what happens if you get it right. If you get it wrong, then exactly the opposite happens and you end up reinforcing all the negative

attitudes and stigma and make your organisation look like it doesn't know what its doing! Using the media effectively requires care and precision.

There are of course many obstacles to using the media but these can be overcome. To begin with most journalists, like most people, have a very low level of knowledge about epilepsy. It also seems to be the case that most of them are not remotely interested in

the condition – why would they be unless they are personally affected?

Taken to the extreme this disinterest can even seem to express itself as unfriendliness or even hostility.

**Give journalists what they want. You have the human interest angle. Journalists love this**

In most countries epilepsy still has a low public and political profile and consequently it languishes near the bottom of journalists' priorities. If it is not perceived to be important enough or of sufficient public interest, why cover it? Ironically, without media exposure, epilepsy will struggle to reach the necessary level of public and political interest needed to excite the media.

In practice, there is no need to be paranoid about all this. The reality is there are thousands of issues and millions of stories out there all competing for coverage. You might feel that the media is turning its back on epilepsy, but I would contend that epilepsy is often overlooked not because it is considered unworthy in itself. It's just that there's some other better story to run at the time. Journalists are a pretty hard headed and hard hearted bunch. They are not going to run a story just to please you. Above all they need a story their audience wants to know about. If that's a story about epilepsy, they'll run it. Your challenge is to give them that story.

**The best stories are about people and epilepsy ultimately is about people**

So, if you want your story in the media, give the journalist what they want and this is where you have one great advantage. You have the human interest angle. Journalists love this. The best stories are about people and epilepsy ultimately is about people. The difficulty here, as we know, is finding people who are prepared to put their lives in the public spotlight, especially if they are concerned about exposing themselves to the possible consequences of stigma. So finding case studies of people prepared to go public about their epilepsy is going to be difficult but it is crucial to getting media coverage.

It's worth remembering that there are more ways to use and access the me-

dia than might appear. Providing news stories or feature articles is one of the more obvious ways. This has the advantage of allowing a degree of control over the content. The most control you are likely to get though is by advertising, where you effectively pay for the media space you use. A less obvious way of entering the media is by 'placing' epilepsy; for example getting it included within a storyline of a popular drama.

A significant barrier to achieving a high media profile is that epilepsy organisations all over the world all have limited resources. There is simply not enough money for major media campaigns, promotional work or advertising. Similarly there are too few experienced or qualified volunteers or professional staff with the skills, abilities and the expertise in communications, public relations, lobbying and media relations to use what limited resources do exist. But, despite this, you can maximise the impact of your resources by focusing and prioritising your media work.

**You must be clear about what you want to communicate. Ideally have just one message and never more than three**

You need to know what type of media you want to use. This is going to be influenced by what options are realistically open to you. You might want coverage on prime time national television news but if you haven't got a story worthy of that, or the money to pay for it, or the contacts in the television company, it's not going to happen.

You needn't limit yourself to a single medium. In fact spreading across television, radio, print media and the internet can massively expand your audience and repetition can reinforce your message as people are exposed to it in different ways and at different times. Remember also that different media work in different ways and what you have to say and who you are trying to reach should influence your choice of which media channel you use.

You must be clear about what you want to communicate. Ideally have just one message for each communication and never have more than three. Use simple language and avoid jargon and acronyms.

Differentiate your audiences and be

focused on the group of people you are trying to reach. You may want to reach the whole of the general public but unless you have the financial resources of an organisation like Coca Cola, it's not going to happen. Break down your audiences into realistically sized and clearly defined groups and target them on a priority basis.

You need to be clear at the outset about the purpose of your media activity. What is it that you want people to know? What do you want them to do? Is it to give you money; is it to have a new attitude towards epilepsy? Is it to use one of your services? In other words, what is it you want to achieve? You should evaluate the effectiveness of your media activity but you can only do this if you are clear right at the start about the outcome you are aiming for.

**Be confident, be persistent, and develop contacts with journalists**

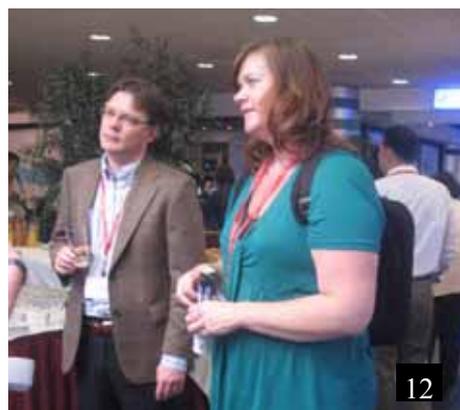
Despite the difficulties, have confidence to use the media and be persistent in your approaches. Develop and nurture contacts with journalists and build long term relationships with them. Understand that they are not going to use every story you run by them but put enough their way and eventually they'll pick something up. Recognise and reward good journalism. This is a great way to make contacts if you don't have any. Not only that but it sets standards within the media for reporting or commenting on epilepsy and it recognises and praises good coverage. Some IBE members do this already, like Epilepsy Scotland and in recent weeks the Excellence in Journalism Award of IBE and UCB Pharma has been launched.

So to finish, let me try and put into practice what I've been saying. Here is the message you need to remember from this article. Using the media is frustrating, difficult and at times almost impossible. However, if you want to address issues of stigma, if you want to raise the level of understanding, knowledge and acceptance of epilepsy in your community then using the media is something you have to do.

Hopefully this article shows that there are things you can do to increase your chances of success.

# Photo Gallery

11<sup>th</sup> European Conference on Epilepsy & Society  
Marseille 2008



**Photo Captions** (all names from left to right)

1. Honor Broderick, Andreas Habberstad, Peter Dahlqvist and Paul Sharkey.
2. Françoise Escarras Gaunet, Deputy Mayor of Marseille.
3. A stand at the Exhibition Area.
4. Mrs and Mrs Kendall loosen up before a session!
5. Ursula Davis, UCB, with Action Zone!
6. Chairman, Norwegian Epilepsy Association.
7. Gus Egan, Congress Secretariat Office.
8. Vania Silva looks after the IBE Stand.
9. Susan Douglas-Scott comments during discussion time.
10. Sonia Molina Perea, a delegate from Spain.

11. Eoghan Magennety, the photo subject for a change!
12. Andreas Habberstad and Helena Lif.
13. Peter Dahlqvist, Sue Mitchell and Kaija Lindstrom.
14. Freedom in Mind exhibition.
15. Seppo Sarkkula, Thanos Covanis and Pierre Genton.
16. A group of delegates from Belgium.
17. A Youth Group Member with Michael Alexa and Annika Katarina Thyselius.
18. Peter Dahlqvist and Jacqueline Beaussart.
19. Members from the Epilepsy Youth Group enjoy dinner.
20. Graham Harding, Hanneke de Boer and Tarun Dua.

*Photos: Susanne Lund, Ragnar Helin and Eoghan Megannety.*



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# COMITÉ LATINOAMERICANO DEL IBE

## V Congreso Latinoamericano de Epilepsia



**Fecha: 5-8 de Noviembre 2008**  
**Lugar: Hotel Radisson Montevideo**

El Congreso fue un éxito en lo académico y asistencia. El Comité LA del IBE, se reunió el día 8 de Noviembre, con la presencia de su directiva:

**Preside:**

- ◆ Dra Lilia Núñez, Mexico

**Vicepresidente:**

- ◆ Dra Elza Marcia Yacubian, Brasil

**Secretario:**

- ◆ Dr Tomás Mesa, Chile

**Past-Presidente:**

- ◆ Dr Carlos Acevedo y Vicepresidente L.A. del Bureau

**Asisten:**

- ◆ Alicia Bogacz, Uruguay
- ◆ Manuel Campos, Chile
- ◆ Alberto Díaz Vasquez, Perú
- ◆ Jaime Fandiño, Colombia
- ◆ Mike Glynn, Irlanda
- ◆ Salvador González Pal, Cuba
- ◆ Serguei Iglesias Moré, Cuba
- ◆ Franklin Montero, R Dominicana
- ◆ Carlos Oliveira y Silva, Paraguay
- ◆ Galo Pesantez Cuesta, Ecuador
- ◆ Noel Plascencia, México.

**Los principales puntos tratados fueron los siguientes:**

Se da cuenta de lo tratado por el Comité Ejecutivo del Comité Latinoamericano del IBE, reunido en

Santiago de Chile durante los días 17 y 18 de Mayo, aprovechando el 55 aniversario de la Liga Chilena contra la Epilepsia. Básicamente se revisó el programa presentado en Paris, al inicio de la misión de este comité y se programaron las reuniones de Montevideo y la conjunta con la Comisión LA del ILAE realizada ayer, 7/11/08.

Se informa de lo tratado en la Reunión del Comité LA del IBE y de la Comisión LA de la ILAE mantenida el 7/11/08:

1. Informe de actividades del Comité LA del IBE
2. Informe de actividades de la Comisión LA de la ILAE.
3. Situación ALADE. Comisión de Educación
4. Próximos congresos LA de Epilepsia

Se conversa de los posibles nuevos miembros como capítulos de países, los que se incluyen R Dominicana y Paraguay. Durante el Congreso hubo avanzadas conversaciones con Bolivia, Honduras y Costa Rica.

Mike Glynn, tesorero del Comité Ejecutivo del IBE, habla sobre los proyectos y cuál son las políticas generales para aprobarlo, recalcando la importancia de una buena presentación y la confianza en la gente que los realiza. Actualmente hay proyectos en Argentina, Ecuador y Guatemala, Se enviará a los otros países estos proyectos, para que tengan un modelo de ejemplo.

El Dr. Carlos Acevedo hace un informe de las actividades regionales latinoamericanas destacando: a) Su rol como un nexo de comunicación entre el Comité Ejecutivo del IBE y la región. b) Ser editor de la revista Epilepsy News, con una sección en español y la posibilidad de hacerlo en portugués. c) Las buenas relaciones con la Comisión LA del ILAE.

Se habla sobre el Congreso de Budapest, cuyo límite de recepción de trabajos se prolonga hasta Diciembre 2008.

Dr Acevedo explica que presentó su re-postulación a la vicepresidencia del Comité Ejecutivo del IBE para Latinoamérica. Mike Glynn, presente en la reunión y actual tesorero del IBE, explica su programa de candidatura a la presidencia del IBE. El otro candidato en el Dr T Covanis de Grecia, es médico y enviarán los currículos de ambos candidatos a la presidencia del IBE.

Dra Núñez refiere que la misión del Comité LA del IBE, está pronto a terminar y habrán nuevas elecciones a comienzos del año 2009. El período será 2009 a 2012 (cuatro años). La directiva del Comité LA del IBE, desea respotular a las elecciones.

Cada país asistente da un informe de las actividades realizadas en el último año.

Tomás Mesa  
Nov 08

# EPI CURE in Berlin

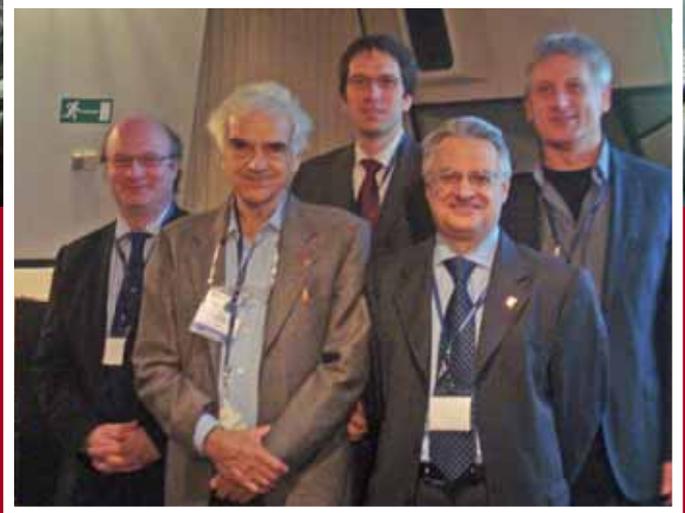
## *EPI CURE Workshop*

8<sup>th</sup> European Congress on  
Epileptology, Berlin 2008

*Report by Janet Mifsud*



Sixth Framework  
Programme Project  
LSH-037315



*Inset photo: Workshop speakers, from left Dr Matthew Walker, Prof Giuliano Avanzini, Dr Holger Lerche, Prof Emilio Perucca, and Dr Thomas Sander.  
Main photo: German Parliament Building*

A workshop organised at the 8<sup>th</sup> European Congress on Epileptology, in Berlin in September provided a great opportunity for the latest developments and research results from the EPICURE project to be presented to other researchers. The main aims of this workshop were to promote the EPICURE initiative to the European scientific epilepsy community.

Prof Giuliano Avanzini related that EPICURE is an EU funded FP6 project which is bringing together a critical mass of EU researchers across Europe (over 30 partners), in order to co-ordinate efforts in the identification of the disease-causing genes of epilepsy and their functional role in the pathophysiology of neuronal excitability and network synchronization, using complementary advanced methods. With responsibility for dissemination of the project, IBE plays an important role in EPICURE

The workshop speakers explained the various work packages being undertaken, and how EPICURE brings together expertise under five main subprojects, which are both clinical and laboratory-based, with the common goal of advancing European epilepsy research, in order to bring about novel therapeutic benefits to patients.

Dr Thomas Sander outlined the research being carried out on the genetics of human epilepsies, while Dr Holger Lerche gave an overview of the research being carried out on the functional analysis of ion channel mutations in genetic epilepsies and pharmacoresistance. Dr Matthew Walker described the work in the work package looking at acquired channelopathies and loss of control excitation, while Prof Emilio Perucca explained how this basic work will be used to devise new possible therapies

for refractory epilepsy.

The workshop clearly showed how excellent results can be achieved if there is central coordination, which will promote cross-fertilization and synergistic effects in epilepsy research in Europe.

Innovation aspects of the project include interactions and synergies between industrial and academic laboratories, by the inclusion of SME participation in the development of improved diagnostic use of contrast agents for MRI investigations, the use of high resolution imaging techniques, and identification of new therapeutic targets and proof of principles for innovative therapy.

Over 100 participants took an active part in the workshop and several questions were put to the speakers by members of the audience.



# A Very Personal Story

My name is Gustaf Nyberg and I'm from Sweden - you know the country of Ingmar Bergman, Abba and Zlatan Ibrahimovic.

When I was 13 years old I received the diagnosis epilepsy. Probably I had it some years before but it was from that age that I started to suffer from it. I was in the beginning of the teenage years and I was going to become one of the best football players in the world. I had just realized that alcohol was something really interesting, as was nicotine also. In short, there was no room for epilepsy in my life. I mean, girls, friends and football were a lot more fun than taking some medicine morning, noon, and night that my parents said I must do.

No, no, no, I was NOT a person with epilepsy, I was going to be a football player or maybe a journalist. Time would prove it.

But after a year something else became a part of life, a part of every second in my life, except perhaps when I was sleeping. I developed a psychosis as a consequence of the epilepsy. Okay, it was a light version of a psychosis, I have realized that now, but anyway, I was not happy. To describe to you how this psychosis would take about two hours, so I will leave that for another time.

But again, epilepsy, and a psychosis as a part of my epilepsy, would not crush my dreams. I was called strange in high school; I was the clown, and that was my escape many times. The tough guys said, "Gustaf - say something funny!" And I would say something funny. They would laugh and say as they went away, "that guy is okay, he's funny; strange but funny." Humour was a bright spot in my life. After school I went home and watched some funny movies or TV-series that I had recorded. I

laughed, I got warm inside, and I would become a comedian. Or a football player. Or a journalist. Time would prove it.

When I was 15 years old I began a theatre course on ABF, which is an adult educational association. And I was home. The course was mainly concentrated on improvisation. I met clowns from several different high schools in the suburb where I was living. The clowns, the lonely clowns, were gathered in the same place on a theatre course in a house in Sollentuna, Stockholm in 1994. And I would become an actor, well a comedian. An actor. Yes!

A year later I saw an advertisement in a newspaper that a theatre group in Solna, another suburb close to Stockholm, was looking for actors of all ages for their production of Bacchae by Euripides. Of course I wanted to play an old Greek tragedy! So in the summer of '95 we played Bacchae in an old ruined castle in The Hagapark outside of Stockholm.

It was a tough time in many ways - my epilepsy and psychosis were very active. But I didn't say a word about it at the theatre, not as I remember anyway. And I think that was a solution in the teenage years for me, not talking about it - not even to myself.

Another solution was my parents. They let me live the life that any other ordinary teenager was living. Of course they knew that I drank alcohol with my friends sometimes, and of course they were worried. And nicotine, off course they didn't like it, they tried to help me to stop it, but I didn't want to. And off course they set a certain time that I had to be home by on weekend nights, but it was the same time as my friends. And I had to do my homework as good as I could, but it was okay to

have mediocre marks. I mean, I was going to become an actor, didn't they understand that? Not a football player, maybe a journalist, but mainly an actor!

So, now it was time for upper secondary school. I started a media class, and I didn't like it. So after a year I had to decide if I should continue with the media course for two more years or start over again, but this time in a theatre class. The choice was not too complicated. So, with a nervous heart I entered my theatre class in the year of 1996. And from the first day, from the first time I opened my mouth, I felt this is right. I met people with the same interest and, in many cases, the same dreams.

Back home where I lived, I still had the same friends I had had since I was five years old. The guys from school and from my football team and so on. The guys I had talked about girls with, the guys I had laughed with, argued with, done nothing on a Friday evening with. You know just walk around, sit on a park bench and talk and smoke. And because I had known them my whole life, my epilepsy was not a big deal for them.

Anyway, upper secondary school in the year of 1996. I was leaving four tough years, unhappy and struggling years. Three wonderful years lay in front of me. In 2000 I had left school, expectant for what life would be like for me.

The spring of that same year I applied for theatre university in Gothenburg, one of four universities in Sweden that educates actors. I got to the third test of four; there were around 30 guys left. I had booked a hotel room in Gothenburg; I had rehearsed the text I had been given with an actor in Stockholm; I was charged. So, I did

## Gustaf Nyberg

is a young Swedish actor who has epilepsy. This is the moving presentation he gave at the 11th European Conference on Epilepsy & Society in Marseille.

(With friends enjoys the Conference Gala Evening in Marseille)



the physical test in the morning and was waiting to do my singing test. After that I woke up in an ambulance on my way to Sahlgrenska, a hospital in Gothenburg. Of course I had had an epileptic seizure.

I was waiting maybe two hours at the hospital without meeting a doctor. You know how it is. And I said to myself "I have the chance of my life. I have rehearsed a lot and I'm close to fulfilling my dream. I can't sit here all day without meeting a doctor. No, no, no I must go back."

And back I went. People of course asked me how I felt and all that, and I said "good, good, nothing special." Almost in the way I had looked at epilepsy all my life.

I did my voice test and was again sitting waiting to do my singing test. Next moment I woke up in Sahlgrenska hospital with a doctor looking at me and two more people around me. I had had another attack and my dream was crushed; I could never become an actor. That was how I felt. This was the start of 4 terrible years. I had to confront my epilepsy. And in the beginning it was an enemy to me. It was a phase I had to go through I think.

Around 2004 I came to a point where I suddenly said, epilepsy is a part of me. Like I have two legs, it's a part of me, or I have brown eyes, it's a part of me. I stopped struggling against it, and it was wonderful, so, so wonderful. That and other things opened doors to a life I love, to MY life. I realized that I am wonderful, and that would mean that my epilepsy is wonderful too. It has given me knowledge, a knowledge that has given me understanding of other persons. Without my tough years - that came from the way I regarded myself and my epilepsy - I would not have

known so much about life as I do now. Thank you tough years for that.

In 2006 I wrote a play called *Thanks, Heaven* and put it on in a theatre called Theatre SAT in Solna near Stockholm. For me it is a very important play. It is a story that describes my view of life. Some people perhaps called it strange and some people took it to themselves. It was a summary of five or six years that I never want to have back, but also years that I don't want to be without.

In spring 2009 I will put on a play called *Kingdom Blackness* in a theatre in Stockholm. It's a political comedy and maybe I won't have so much of my own life in the story. This time it's maybe more about my view of life and society. So if you are in Stockholm in April 2009 you are very welcome to see this magnificent play!!

Today I work on different projects. Part of the time I work in the health-care sector with music, dance and drama. I am also a personal assistant to two 13 year old guys. And of course theatre takes a lot of my time. Most of my friends are involved in theatre and, to be honest, theatre has helped me a lot and I am grateful for that. It has given me self-confidence and a place to call home.

But a lot of different things made me feel happier with being me. Partly I started to exercise. I walked for hours. And walking helped me to solve my thoughts. After walking for an hour my problems don't feel so big anymore. And I also started to eat healthier food. Fruit and vegetables. I tried never to go hungry. I started to drink water instead of sugary drinks. At the beginning that was more of an economic decision but it made me become a little bit calmer. My pulse rate went down. And after attempt

number 29,000 I finally stopped using nicotine. I'm still far happier for that, after 5 and a half years. And a very big reason was how I slowly began to look at myself in a different way. To love myself has taken me 6 years and that love is still growing. Because it's a fact, the more you love yourself, the more you look at the world and the people around you with lovely glittering eyes. People have talked about it for a thousand years but I want to say it again. It's not so complicated. It has been my biggest solution.

Because we are talking about achieving goals, and the goals you achieve are not worth anything in the long run unless you love yourself, or like yourself, if you prefer to say that. It is the basis. By liking yourself you become strong and not so vulnerable. It's the solution.

Finally, as I said before, I even grew to love my epilepsy. Truly, I mean truly, love my epilepsy. It's not just words. My epilepsy and the things that came from it have made me wise. Without my crises I maybe wouldn't have started working for myself, or knowing that much about fear and so on. It has given me yin and yang. It has made me whole as a human being. Thank you epilepsy for that!

So - to become friends with your epilepsy, accept it, love it and see what it has given you.

And then, try to achieve the goals you want. If you don't achieve them, try again, at least your epilepsy won't stop you. It can help you. In what way? You decide.

# 28th International Epilepsy Congress Budapest, Hungary June 28th—July 2nd 2009



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[www.epilepsybudapest2009.org](http://www.epilepsybudapest2009.org)