

INTERNATIONAL

# Epilepsy News

# 50 Years

## Shining a light on Epilepsy





## Rome Congress now on the horizon

Since becoming President of the IBE in 2009 I am pleased to report that, despite the global recession, we have made significant strides in the great cause of epilepsy. The 29<sup>th</sup> International Epilepsy Congress, which is being held in Rome, the city where the IBE was founded by the motion of Dr Abraham Moscovich, in 1961, is the high point of 50 years of achievements and developments.

Earlier this year the IBE launched the 'Epilepsy Without Words' photography competition which received over 300 entries. The winners will be announced at the congress and an exhibition of the 50

best photographs will be on display. An impressive poster display highlighting the initiatives, achievements and plans for the future from over 110 IBE members has also been arranged.

A documented history of the IBE will provide members with a keepsake of the origins and significant developments achieved by the IBE for all those living with epilepsy. This booklet, which was compiled by Hanneke De Boer, with design and layout by Susanne Lund and Ann Little, will also be available on our website.

During the congress, participants will be able to enjoy the Milestone Walkway, a colourful exhibition highlighting the purpose and goals of the International Bureau for Epilepsy over the past 50 years.

The major social event of the congress will be a concert in Auditorium Conciliazione,

the site of the 1961 congress where IBE was founded. Prof Federico Vigevano from Rome has done tremendous work to bring this event to fruition and, on behalf of all in IBE, I wish to thank him warmly for this great achievement.

I hope I will be able to meet many of you in Rome as we celebrate IBE's 50th birthday with these, and other, special events.

All the best,  
Mike Glynn  
President



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#### WHO

IBE is in official relations with the World Health Organisation (WHO).

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# Warm greetings and thank you!

In the two years that have passed since the General Assembly that was held in Budapest in 2009, the objectives of IE News have essentially remained the same. In other words, it is an important medium of news and information for all IBE members, the public, and people with epilepsy and their families.

The newsletters provides the opportunity to relate the main activities of the International Executive Committee, presided over by Mike Glynn; to highlight the most important regional activities through its Sub-editors; to provide information about international and regional congresses; to

present details on the activities of IBE's working groups and Task Forces; as well allowing a platform to promote initiatives of high impact such as IBE's star project, the Promising Strategies Program, in which many IBE members have been favored with financial support to develop initiatives.

We have had interviews with important figures in the world of epilepsy, including some IBE members. Of particular interest is the story in parallel of IBE's history, written by Harry Meinardi, and the ILAE history by Ted Reynolds. We have tried to make the magazine contents entertaining, useful, original and well-designed - with a new layout introduced in the last issue. We have asked for your suggestions for improvement and we appreciate the observations and regular collaborations that you have sent us, so that we can be proud

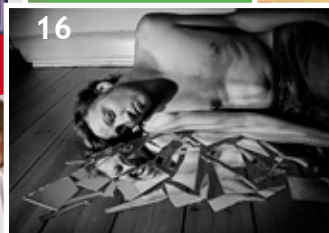
of our newsletter. Now as we approach the next General Assembly, taking place in Rome in the midst of IBE's Golden Jubilee celebrations, please accept a special and warm greeting on my behalf and on behalf of all those behind the publication of each issue of IE News, in particular to Ann Little.

Sincerely yours,

Dr Carlos Acevedo.  
IE News Editor.

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# Promising Strategies Program 2011



## SWAZILAND Poultry Rearing

With 69% of Swazis living below the poverty line, the situation for people with epilepsy is even more difficult. The Swaziland Epilepsy Association is launching a poultry rearing project to improve the socio-economic status of people living with epilepsy and other disabilities, by providing them with a job.

The project will also help to promote independent living and better self-esteem amongst members of the association's support group.

Day-old chicks will be raised to maturity and then sold to generate profits. Ten per cent of the mature chickens will be retained to replenish stock and to ensure sustainability of the project.

**T**he China Association Against Epilepsy (CAAE), a nationwide professional social organization, was officially inaugurated with the approval of the Ministry of Civil Affairs of China in June 2005. There are around 9 million people with epilepsy in China, including 6 million people with active epilepsy. Moreover, there are an additional 0.4 million new cases diagnosed each year.

Based on these figures, it is estimated that there are approximately 30 million epilepsy carers (including parents and relatives) in China. Caring for a person with epilepsy is often a difficult task; taking its toll physically, mentally and emotionally. The economic burden of each family is huge, especially for people living in rural areas.

The aim of this project is to promote public awareness for carers of people with epilepsy and to improve their quality of life. The project will investigate the mental health, quality of life and economic status of carers; and will also encourage carers to communicate and exchange their experiences.

## CHINA Caring for the Carers



## NEPAL Documentary Film



Although Nepal boasts grandeur in its cultural and natural diversity, more than 75% of the population is still dependent on agriculture and more than 70% of the population lives below the poverty line. About 1% of the population is living with epilepsy and many unrecorded deaths could be due to epilepsy and related diseases.

Nepal Epilepsy Association (NEA) is producing a documentary as a means of increasing awareness about epilepsy. The short documentary will focus on the social stigma of epilepsy, its impact on society, and on the possible ways of prevention and treatment of the disease.

Post production, it will be broadcast on various national television channels, including the government-owned TV channel. The film will also be shown to local people who come for their treatment to various camps, as well as in NEA's epilepsy clinics at Lazimpat, Kathmandu and Dolakha.



The Foundation for the Rehabilitation of people with Epilepsy (FIRE) is a nonprofit institution created in 1975 by the Colombian League against Epilepsy and the Cartagenian community, to offer integral support to people with epilepsy and other associated disorders and disabilities.

The aim of the HomeClinic project is to help people with epilepsy and their families through the creation of a welcoming space, where pupils can develop basic life skills such as independence in dressing, feeding, bathing and other everyday activities. The general purpose is to educate with dignity, regardless of the physical or mental health of the person, using individual and group activities, involving the family and the community. HomeClinic hopes to improve the quality of life of those attending the course, and their families.

The program is for young children with epilepsy and associated syndromes in the age group of 4 to 10 years of age.

## ECUADOR Neuropsychomotricity

Neuropsychomotricity is a modern, interdisciplinary science, framed in the context of neuroscience, which provides guidelines for the harmonic development of the individual. It bases its principles on a combination of neurology and psychomotricity, taking as basic the concept of the mental-physical structure unit.

The National Center for Epilepsy is a charitable institution mainly focused on the low income sectors of Ecuador. It was founded in 1989 and has a multidisciplinary team to treat people with epilepsy and their families. The centre is also developing strategies for dissemination of information in the community about the reality of this disorder.

Through a recent partnership agreement signed between the National Centre for Epilepsy and the Ministry of Education of Ecuador, there is an intention to spread neuropsychomotricity to professionals working in the field of psychology and health in schools, so they can apply this support directly to children with psychomotor difficulties and epilepsy.



The population of the Islands in the Western Pacific region is over 2 million, with an estimated 40,000 people with epilepsy. It is unclear what epilepsy and neurological services are available in the islands. Neither are there data regarding the treatment gap or the cost of epilepsy medication.

To establish information on the situation for people with epilepsy in the Pacific Islands, Epilepsy New Zealand has proposed a project with the following objectives:

- Conduct research into the epilepsy services available to the Pacific Islands in the IBE Western Pacific Region, with a view to introducing and/or improving services.
- Quantifying the treatment gap and implementing measures and services to reduce it.
- Establish longterm self-sufficient service organisations, connected to the IBE, in each island nation.

The **IBE Promising Strategies Program** is now 5 years old and is one of the most successful of all IBE's initiatives. Set up in 2006, as a means of supporting members through the provision of financial support for projects aimed at improving the quality of life of people with epilepsy, to date **50 projects in 33 countries** have received a total of **US\$250,000** in support.



The Indian Epilepsy Association provides services to support educational activities such as continuing medical education programmes, training programmes in epilepsy for general practitioners and occasional education forums in epilepsy for people with epilepsy.

In India, it is difficult for people with epilepsy to find employment due to the discrimination that surrounds epilepsy. Through this project, the association will train a group of people with epilepsy in the craft of baking and bakery management. Training will be provided by qualified bakers who are already running successful units. The students will be given support to purchase raw materials and will also be trained in management skills. This training will give them confidence to establish their own business, which will in turn improve their morale and quality of life.

## Epilepsy Awareness

Epilepsy is one of the most common neurologic disorders in the world. However, in Tibet, due to its special geographical location, there is very little awareness about epilepsy amongst the public. The unique religious beliefs have increased negative attitudes towards patients with epilepsy and their treatment. Many Tibetans believe seizures are caused by demons and seek out cures through religious rituals.

The objectives of this project are:

- To promote epilepsy prevention and knowledge in local medical workers, to empower them to provide guidance and treatment to patients.
- To promote understanding of epilepsy in people with epilepsy and their family members, and to motivate them to seek medical treatment.
- To promote epilepsy prevention and increase public awareness.



In Zimbabwe, as in most parts of Africa, epilepsy is misunderstood and, as a result, people with the disease suffer stigma, exclusion and discrimination. This is a major reason why people with epilepsy are not receiving treatment.

The Epilepsy Support Foundation (ESF) is a registered voluntary organization, established in 1990, to support the welfare of people living with epilepsy through treatment, education, awareness, advocacy, networking, medication, diagnosis, counseling and social support services.

This project consists in initiating an innovative lobbying and advocacy programme whereby people with epilepsy speak and write about their condition, successes and challenges. These testimonies will be available in books, DVDs and as adverts in the print and electronic media. The testimonies will be produced in different dialect languages.

**Next Call:** Information on all of the **50** projects that have been funded to date can be found on the IBE website, where you can also find information on funding criteria. [www.ibe-epilepsy.org/promising-strategy](http://www.ibe-epilepsy.org/promising-strategy). The next call for **Letters of Intent**, for projects to be considered for funding in 2012, will be circulated to all IBE member associations in late September 2011.



## LITHUANIA Legislation Survey

Lithuania has registered 24,000 people with epilepsy, of whom 20% are employed, 30% have special training and 37% have only their disability pensions as a source of income. Research undertaken by LESIA (Lithuanian Association for the Integration of People with Epilepsy) has shown that people with epilepsy are discriminated against in the areas of education, vocational training and employment.

With this project, LESIA will conduct an analysis of the laws in the social sphere in the light of the UN Convention of the Disabled. Surveys will be carried out amongst people with epilepsy regarding treatment quality; quality of life; and the impact of legislation for people with epilepsy in finding employment in the free labour market. The results of the project will be an evaluation of existing laws and drafting of amendments for consideration and adoption by the Parliament of Lithuania.



## Soccer Camp

**HAITI**

**33 Project covering all seven IBE regions, have received support from the Promising Strategies Program Fund.**

- |                   |                             |
|-------------------|-----------------------------|
| 1. Argentina      | 19. Mongolia                |
| 2. Bangladesh     | 20. Namibia                 |
| 3. Brazil         | 21. Nepal                   |
| 4. Cameroon       | 22. Philippines             |
| 5. Chile          | 23. Romania                 |
| 6. China          | 24. Sierra Leone            |
| 7. Colombia       | 25. South Africa            |
| 8. Czech Republic | 26. Swaziland               |
| 9. Ecuador        | 27. Tanzania                |
| 10. Ethiopia      | 28. Tibet                   |
| 11. The Gambia    | 29. Togo                    |
| 12. Guatemala     | 30. Uganda                  |
| 13. Haiti         | 31. Western Pacific Islands |
| 14. India         | 32. Zambia                  |
| 15. Kenya         | 33. Zimbabwe                |
| 16. Lebanon       |                             |
| 17. Lithuania     |                             |
| 18. Mauritius     |                             |

Children with epilepsy in Haiti are excluded from all activities including, sometimes, schooling. With this project the Canadian Epilepsy Alliance will organise a 2-week soccer camp during the summer for children aged between 7 and 16, girls and boys with epilepsy, regardless of their levels. During this time, the children will be involved in play-and-learn activities cared for by well trained soccer teachers, volunteers and medical professionals

Trainings will focus on technical-tactical coordination and will be provided in a fun way. The physical portion of the camp aims to educate young people about physical activity. It will also convey the values of mutual respect and openness to others, values that accompany the conduct of all activities.

During the educational part of the camp, physician and nurses will teach children about basic hygiene, good eating and sleeping habits as well as answer questions about epilepsy. Volunteers will also participate in cultural activities with the children, including reading, singing and dancing sessions.



# THE ORIGINS OF THE INTERNATIONAL LEAGUE AGAINST EPILEPSY

ESTABLISHED 1909

## Before and during the Second World War

**In Issue 3-2010 of IE News Ted Reynolds described how the ILAE and its journal *Epilepsia* were founded by a group of European neurologists and psychiatrists in Budapest in 1909, but, following a very encouraging start, ceased to exist after the outbreak of World War I in 1914. The story continues, looking at the period before and during World War II.**

The International League Against Epilepsy (ILAE) and *Epilepsia* were not revived until the summer of 1935, during the second International Congress of Neurology in London. That congress was dedicated to the centenary of the birth of Hughlings Jackson for which a special medal was given to the delegates. Epilepsy was therefore a main theme of the congress.

On the 31<sup>st</sup> July, 32 delegates with an interest in epilepsy, from 14 countries, met at Dormans Park Hotel, close to the Lingfield Colony in Surrey, and resolved to re-launch the ILAE and *Epilepsia*.

At a subsequent meeting, on the 2<sup>nd</sup> August in London, William Lennox (USA) was elected President, Louis Muskens (Netherlands) Vice President, HI Schou (Denmark) Secretary and Editor of *Epilepsia*, and Tylor Fox (Lingfield, UK) Treasurer. Muskens, who died in 1937, was the only link with the past. He had been the leading advocate of the revival of the League and he now proposed, wisely as it proved, an American President to avoid the catastrophic politics of Europe at that time.

Although the new vision of ILAE was similar to that of its original founders, there would now be a greater emphasis on the social and institutional care of patients with epilepsy, in part because of the large number of new neurological and psychiatric journals, since World War I, in which



epilepsy research could now be published.

The new second series of *Epilepsia*, published once a year from 1937 onwards, reflected this new policy, including reports of the activities of the League and of its Chapters.

At first, however, there were only three Chapters i.e. America (86 members), Britain (102) and Scandinavia (31), but with 29 members from countries without Chapters. By 1938 Chapters were also formed in the Netherlands and the former Czechoslovakia (now the Czech Republic and Slovakia).

It was agreed that the ILAE would henceforth meet every 4 years. The following meeting took place on August 24<sup>th</sup> 1939,

### Dormans Park Hotel, Lingfield

at the third International Congress of Neurology in Copenhagen, in the shadow of the Second World War, which broke out while the congress was taking place. Lennox described the banquet as a tragic affair. A new Constitution for the League was approved and the original officers were re-elected, the exception being KH Stauder of Germany who replaced the deceased Muskens as Vice President; although there was no Chapter in Germany with whom war was imminent.

Unlike the First World War, the League managed to survive the Second World War thanks to the continuing endeavours of its only active Chapter in America.



Although *Epilepsia* continued to appear annually, Schou found it impossible to edit the journal in Denmark and this task was undertaken by President Lennox.

Annual Chapter meetings continued in the USA with a research focus especially in the field of electroencephalography and new treatments with phenytoin and related anti-epileptic drugs.

Lennox also initiated a "Laymans League" in America of which there were nearly 2,000 members by 1946, a forerunner of later lay Chapters and IBE.

***In the next issue of IE News, it will be the turn of Harry Meinardi to continue his history on the origins of IBE.***

#### References:

Reynolds EH, *The John Hughlings Jackson 1935 Centenary Congress Medal. J.Neurol.Neurosurg. Psychiatry* 2005; 76:858-859.

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The Hughlings Jackson centenary medal

## A snapshot of IBE's first 50 years



50 years  
focussed on Epilepsy



International Bureau for Epilepsy  
1961 - 2011



A special keepsake publication, that looks back at 50 years of IBE activities, is one of the Golden Jubilee initiatives created to celebrate the Bureau's special anniversary.

Compiled by Hanneke de Boer, and with a stunning cover designed by Susanne Lund, the booklet will be available, free of charge, to delegates at the 29<sup>th</sup> International Epilepsy Congress in Rome.

The publication will also be available to all visitors to the IBE website.

# Condecoran a Médico Chileno Chilean Neurosurgeon Awarded

*Carlos Acevedo reports*



El destacado Neurocirujano chileno, Dr. Manuel Campos, recibió en abril del presente año una condecoración al servicio público, entregada por la Municipalidad de San Isidro del Perú. Este galardón fue otorgado por su trabajo desinteresado a niños con epilepsia de escasos recursos de ese país. El profesional realizó varias cirugías de epilepsia, en forma gratuita, en conjunto con neurocirujanos de ese país, en el Hospital Almenara de la Seguridad Social del Perú, cuyo objetivo fue lograr librar de sus crisis a los pacientes afectados y por consiguiente mejorar la calidad de vida de los mismos.

El Dr. Manuel Campos es egresado de la Universidad de Valparaíso con un Doctorado en la Universidad de Bonn, Alemania. Además, es Past-President de la Liga Chilena contra la Epilepsia, Presidente de la Comisión Latinoamericana de la Liga Internacional contra la Epilepsia y Director del Centro Avanzado de Epilepsias, en la Clínica las Condes, en Santiago de Chile.

Las cirugías realizadas se conocen por el nombre de "Hemisferectomía funcional", técnica que por primera vez se lleva a cabo en el Perú. Al recibir la medalla, el Dr. Campos destacó: "Lo común de quienes recibimos esta distinción es: servir sin esperar nada a cambio". Además, hizo un llamado para que se desarrolle la cirugía de la epilepsia en Perú. "Las epilepsias afectan a más de 300.000 personas en el Perú. Un 30% siguen con crisis pese a los fármacos, es decir más de 100.000 personas. En este grupo, podemos hacer cirugías y lograr que más de dos tercios queden totalmente libres de crisis para siempre", afirmó.

La Municipalidad de San Isidro de Perú, en su aniversario de 80 años, condecora además a otras personas que se distinguieron por su servicio ofrecido a la comunidad: el Sr. Javier Pérez de Cuéllar, ex-Secretario de las Naciones Unidas, por dos períodos de servicio; el Sr. Carlos Neuhaus, ex-Alcalde, por tres períodos de servicio.

En el campo de la cirugía de la epilepsia, esta iniciativa constituye un modelo de cooperación en el terreno de la epilepsia, para países vecinos de una misma región, lo cual que debemos fomentar, ya que puede ser llevada a cabo de forma similar en otras regiones del mundo.

En el campo de la epilepsia, esta iniciativa constituye un modelo de cooperación que se debe fomentar, de este modo países vecinos de una misma región la pueden llevar a cabo de igual manera.

Dr Manuel Campos, a distinguished Chilean neurosurgeon, was decorated in April 2011 by the Municipality of San Isidro, Peru for his service to the public. The award was presented to honour his generous work which he has performed for underprivileged children with epilepsy in Peru. Dr Campos performed several epilepsy surgeries free of charge, working alongside neurosurgeons from that country, at Peru's Almenara Social Security Hospital, with the goal of helping those patients become seizure-free and thus to improve quality of life.



MANUEL CAMPOS

Dr Manuel Campos graduated from the University of Valparaíso in Chile, and has a PhD degree from the University of Bonn in Germany. He is Past President of the Chilean League against Epilepsy; President of the Latin American Commission of the International League against Epilepsy (ILAE); and Chief of the Advanced Center for Epilepsy in Las Condes Clinic in Santiago, Chile.

The surgeries performed were so-called "Functional Hemispherectomies" and this was the first time for this type of surgery to be carried out in Peru. On receiving his medal, Dr Campos emphasized the following: "When we give, we commonly do not expect to receive something in return". He also made a call asking for epilepsy surgery to be developed in Peru. "Epilepsy affects more than 300,000 people in Peru, 30% of whom (that is, more than 100,000 people) suffer from seizures, despite antiepileptic medication. Through surgery, two thirds of those people could become seizure free", he stated.

The San Isidro Municipality, celebrating its 80<sup>th</sup> anniversary, also awarded two others in recognition of work carried out by them for the community: Dr Javier Pérez de Cuéllar, former Secretary of the United Nations (UN); and Mr Carlos Neuhaus, former Mayor.

In the field of epilepsy, this initiative represents a cooperation model that must be promoted, so that neighboring countries of the same region can also have access it.

# European Written Declaration on Epilepsy

Following on the success of the first European Epilepsy Day, held in Strasbourg as well as throughout Europe in February, a European Advocates for Epilepsy working group of MEPs (Members of the European Parliament) with an interest in epilepsy, was created. Already, 30 MEPs from 18 different EU countries, have joined this group. A first activity of the group was the submission in April of an EU Written Declaration by Mr Gay Mitchell MEP, President of the European Advocates for Epilepsy Group, and co-signed by four other MEPs.

## The process

EU written declarations are printed, translated and posted in a register at the European Parliament. The register is public and is kept outside the entrance to the Chambers in Strasbourg and Brussels during plenary sessions. Declarations are also published on the Parliament's website.

The Written Declaration on Epilepsy was ready for signing in time for the May plenary session in Strasbourg. Thereafter MEPs were able to sign it during the plenary sessions in Strasbourg in June, July and September and during the June mini session in Brussels. These sessions, usually lasting 4 days each month, are the only times when the books are open for signatures. And even then, the books are only available during voting periods and discussion sessions.

To have a Written Declaration carried requires the signature of a **majority** of MEPs. With the total number of MEPs being **738**, this means we must achieve a minimum of **369 MEP** signatures. If the required number of signatures is not received by the closing date of the declaration, which for the Written Declaration on Epilepsy is 15<sup>th</sup> September, then it lapses. There is no second chance!

## The value

If approved, the Written Declaration on Epilepsy will be a very valuable document

to use at local and European level, for example:

- in advocating for increased research funding;
- advocating for improved healthcare facilities and services provision for people with epilepsy;
- building other significant initiatives at European level.

In addition, MEPs can use the declarations to launch or relaunch initiatives that come within the EU's remit.

## The plan of action

The most important people in convincing MEPs to sign the declaration are groups and individuals at national level – because these are the people who voted them into office! So far, both IBE member associations and ILAE chapters in EU countries have been very supportive in writing to their MEPs just prior to each plenary session. So fantastic been the response that our progress to date has been as follows:

- At the end of the May plenary session we had **107** signatures
- At the end of the June plenary session we had **245** signatures
- At the end of the June mini-session in Brussels we had **275** signatures
- At the end of the July session we had **347** signatures.

This means that we need to get just 22 more signatures during the September session to have the declaration carried and signed by the European Parliament. To be able to say that 369 (or more) MEPs across Europe recognise and support the need for improvement in both the medical and social aspects of epilepsy is a very strong argument indeed!



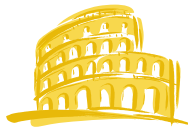
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# CONGRESS AWARDS

The IBE/ILAE congress awards are presented biennially at the time of the International Epilepsy Congress, to honour individuals who have made significant contributions, over a long period of time and at international level, in the field of epilepsy. There are three categories: Ambassador for Epilepsy - presented to a maximum of 12 recipients; Social Accomplishment, presented to one individual; and the highest honour, Lifetime Achievement Award which, as its name implies, recognises a lifetime of achievement of an individual.

## Lifetime Achievement Award

*This is the highest award bestowed by IBE/ILAE and is given to an individual to recognise his or her exceptional and outstanding personal contribution over a long period of time to activities to advance the cause of epilepsy.*

**Presented to: Jerome (Pete) Engel Jr. MD, PhD, USA**



Jerome Engel, Jr. is Director of the Seizure Disorder Center, The Jonathan Sinay Distinguished Professor of Neurology, Neurobiology, and Psychiatry and Biobehavioral Sciences, and a member of the Brain Research Institute at UCLA. He received his undergraduate degree from Cornell University, his advanced degrees from Stanford University, and completed his training in neurology at Albert Einstein College of Medicine.

Pete Engel is a Past-President of the International League Against Epilepsy, the American Clinical Neurophysiology Society,

the American Epilepsy Society, and is past Co-Chair of the Global Campaign Against Epilepsy.

His bibliography lists more than 1,000 publications and 30 books, including *Epilepsy: A Comprehensive Textbook*, *Surgical Treatment of the Epilepsies*, and *The Treatment of Epilepsy*. He is principal investigator on three research grants from the National Institute of Neurological Disorders and Stroke, and has received numerous awards and honors, including a Fulbright Scholarship, a Guggenheim Fellowship, and a Javits Award.

## Social Accomplishment Award

*Every two years, one person who has carried out outstanding activities aimed at improving the social circumstances of people with epilepsy, over a long period of time, is recognised.*

**Presented to: Dr Pravina Shah, India**



Dr Pravina Shah was Professor and Head of Neurology at King Edward Memorial Hospital in Mumbai, India for 19 years. She is the immediate Past President of the Indian Epilepsy Association (IEA) and currently consults at Fortis Hospitals. She pioneered the support group movement in India and started E-Cell, a dedicated centre to care for people with epilepsy.

Dr Shah worked tirelessly to dispel myths and taboos about epilepsy, engaging with the media and reaching out to opinion leaders in government.

She initiated a unique epilepsy awareness programme to educate thousands of school children in Mumbai. She conducts regular epilepsy camps for the impoverished, marginalized rural populations.

Passionate about her work; compassionate towards all; a leader who empowers; and a visionary who sensitized India to psychosocial issues of epilepsy; Dr Shah says that, in her journey with epilepsy, she is a 'taker' not a 'giver', having been enriched by learning from the lives of people with epilepsy.

## Ambassador for Epilepsy Award

The Ambassador for Epilepsy Award is the oldest IBE/ILAE award, having been introduced in 1968. To date, a total of 287 worthy recipients received an Ambassador pin to reflect international peer recognition and which is given for the lifetime of the recipient. Twelve Ambassadors will be presented with their awards in Rome.



**Susan Axelrod, USA**

Chair and founder of Citizens United for Research in Epilepsy (CURE), Mrs Susan Axelrod has received numerous awards and honours for her leadership from Research America, Child Neurology Foundation, and the American Epilepsy Society. She has served on the National Institute of Health's (NIH) National Advisory Neurological Disorders and Stroke Council.



**Hasan Aziz, Pakistan**

Prof Hasan Aziz is credited with initiating general neurology in Pakistan 40 years ago, which has focused on epilepsy for the last 25 years. He is an Executive Committee Member and immediate Past President of the Epilepsy Association of Pakistan. He has served on various ILAE Commissions. Presently he is a member of the Commission on Asian and Oceanian Affairs.



**Lionel Carmant, Canada**

Dr Lionel Carmant is Professor of Pediatrics at University of Montreal and developed, along with colleagues at the university, an epilepsy programme for the care of the patient through the lifespan. He has also worked on improving epilepsy care globally including the development of projects in Haiti, Dominican Republic and with the Commission for African Affairs.



**Jaime Fandiño-Franky, Colombia**

Dr Jaime Fandiño-Franky is Past President and founder of the Colombian League Against Epilepsy and Founder and Executive Director of Foundation for Rehabilitation for people with Epilepsy (FIRE). He is a founder of several epilepsy surgery programmes in Colombia and is founder of a Neurological Hospital devoted to Epilepsy Surgery in Cartagena.



**Andres Kanner, USA**

Dr Andres M Kanner is Professor of Neurological Sciences and Psychiatry at Rush Medical College, Chicago. He has long-standing research interests in the pharmacologic, surgical and psychiatric aspects of treatment-resistant epilepsy. He is on the Editorial Board of *Epilepsia*, *Epilepsy & Behavior* and *Epilepsy & Seizure* and is associate editor of *Epilepsy Currents*.



**Weiping Liao, China**

Dr Weiping Liao is Vice President of the China Association Against Epilepsy and an editorial board member of *Epilepsia*. As a member of the Asian Epilepsy Academy, he has organized and contributed to over 20 epilepsy workshops and five Asian & Oceanian Epilepsy Congresses. Dr. Liao is also the Director of the Institute of Neuroscience at Guangzhou Medical University.

## Presentation of Ambassador for Epilepsy Awards

The Ambassador for Epilepsy Awards, together with the Social Accomplishment and Lifetime Achievement Awards will be presented during the Opening Ceremony of the congress in Rome on Sunday 28th August 2011.



### Wolfgang Löscher, Germany

Wolfgang Löscher is Professor and Director of the Department of Pharmacology, Toxicology and Pharmacy at the University of Veterinary Medicine Hannover; he is also Head of the Center for Systems Neuroscience in Hannover. He has over 400 referred publications and received awards for his research, including the American Epilepsy Society's Epilepsy Research Award for Basic Science Research in 2006.



### Eli Mizrahi, USA

Eli M. Mizrahi, MD is Chair of the Dept of Neurology and Professor of Neurology and Pediatrics, Baylor College of Medicine, Houston. He represents ILAE on issues related to neonatal seizures, and epilepsy of infancy and childhood, as a member of the Commission on Pediatrics, the ILAE/WHO Task Force on Neonatal Seizures Guidelines, and the Task Force on Guidelines for Seizures in Infancy.



### Rosemary Panelli, Australia

Dr Rosemary Panelli has worked with Australian epilepsy services for 16 years and championed inclusion of peer support workers in epilepsy care teams. Her research shows the model's potential to enhance care. She has worked to improve understanding of epilepsy-related risks and death, through Australian epilepsy memorial services and publication of Sudden Unexpected Death in Epilepsy: a global conversation (2005, 2011).



### Asla Pitkänen, Finland

Asla Pitkänen is Prof of Neurobiology in the University of Eastern Finland. She is Co-Editor-in-Chief of *Epilepsy Research*. Awards include the Jan Evangelista Purkyně Honorary Medal and the ASPET Award. In 2010, she was elected to the Finnish Academy of Science and Letters. She served on national and international committees, including Finnish Epilepsy Society, Brain Research Society of Finland, EU, NIH-NINDS, ILAE, and FENS.



### Steven Schachter, USA

Dr Steven Schachter is Professor of Neurology at Harvard Medical School, and Senior Neurologist at Beth Israel Deaconess Medical Center, Boston. He is Co-Chair of the ILAE Therapeutics Strategies Commission and serves on the ILAE/IBE Global Campaign Task Force. He is Past President of the American Epilepsy Society, past Chair of the Professional Advisory Board of the Epilepsy Foundation and founding editor-in-chief of *Epilepsy & Behavior*.



### Walter van Emde Boas, Netherlands

Walter van Emde Boas is honorary member of many national and international scientific societies, a frequent lecturer on EEG diagnosis, presurgical evaluation and surgical treatment of epilepsy in adults and children, and is co-author of over 60 peer reviewed journal papers and book chapters. He has served on the ILAE Commissions on Classification and Terminology, on Neurosurgery and on Education. He chairs the taskforce on Distance Education.

# Strategic Plan for Epilepsy in the Americas

Dr Carlos Acevedo, IBE Secretary General reports

La iniciativa de desarrollar un plan estratégico para la epilepsia en la región de las Américas es consecuencia de la meta de la Global Campaign (GCAE) Task Force. Es así como en el 6º Congreso Regional LA de Epilepsia desarrollado en agosto del año 2010, realizó una reunión con participación de: ILAE, Nico Moshé; Bureau: Mike Glynn; El secretario de la GCAE representando por H de Boer; los Vicepresidentes LA IBE e ILAE y el Regional Mental Health Advisor PAHO, Dr Jorge Rodríguez. En dicha reunión se acordó emprender esta iniciativa, lo cual después de un arduo trabajo realizado entre octubre 2010 a mayo 2011, con input de toda las regiones de las Américas de IBE e ILAE y los estamentos técnicos de la PAHO en Washington y WHO, produjeron este documento.

La importancia de este plan estratégico es que compromete a todos los países firmantes a incluir a la epilepsia como una prioridad dentro de los planes nacionales de salud los próximos 10 años y esto por vez 1ª en los 100 años de existencia que tiene PAHO. Esto constituirá una enorme ayuda a todos los pacientes en sus tratamientos y especialmente en su calidad de vida.

En la reunión del Comité Ejecutivo de PAHO realizada en Junio pasado el Plan Estratégico para la Epilepsia en las Américas fue aprobado con observaciones menores de parte de EEUU, México y Perú, las cuales fueron acogidas y se llegó a un texto final que ya está disponible en la Pagina Web de PAHO. En última semana de Septiembre de este año el Plan Estratégico será presentado en la reunión anual de todos los Ministros de Salud de las Américas, oportunidad en la cual fueron invitados oficialmente a participar el Dr Carlos Acevedo y el Dr Marco Tulio Medina quienes colaboraron en todas las etapas de la elaboración del Plan estratégico representando IBE e ILAE respectivamente. Luego de la aprobación y firma oficial del proyecto por los Ministros, entre el 21 y el 23 de Octubre de este año se procederá al lanzamiento oficial del Plan Estratégico en un taller Regional a efectuarse en Honduras, oportunidad en la cual participaran como expositores Mike Glynn presidente del IBE, Nico Moshe presidente de ILAE, Hanneke de Boer en representación de la GCAE, Tarun Dua por WHO, Gary Mathern for the IOM (Institute of Medicine), Carlos Acevedo IBE y Marco T Medina ILAE. En este Taller se darán los primeros pasos para el inicio del desarrollo del Plan Estratégico en todo el continente Americano.

The Strategic Plan for Epilepsy in the Americas is one of the goals of the Global Campaign Against Epilepsy (GCAE) Task Force. It is for this reason that, during the 6<sup>th</sup> Latin American Congress of Epilepsy in August, 2010, a meeting was held whose participants included: Nico Moshe from ILAE; Mike Glynn from IBE; Hanneke de Boer as GCAE Secretary; the Latin American Vice-Presidents of ILAE and IBE; and Dr Jorge Rodríguez, as PAHO Regional Mental Advisor. During this meeting, the participants agreed to develop the idea for the Strategic Plan, and following diligent work carried out between October 2010 and May 2011, with the feedback of all the IBE and ILAE Regions and with the collaboration of PAHO and WHO in Washington and Geneva, several drafts were prepared.

What is important is that this Strategic Plan involves every country that is in favor of including epilepsy as a priority in its National Health Plans for the next 10 years and for the first time in 100 years of PAHO's existence. This will be very significant for the treatment of people with epilepsy and especially for their quality of life.

At the meeting of the PAHO Executive Committee, which took place in late June, The Strategic Plan for Epilepsy in the American Region was approved with minor observations on the part of the United States, Mexico and Peru. These comments were addressed and a final text was agreed, which is now available on the PAHO website. In the last week of September the Strategic Plan will be presented at the annual meeting of all Ministers for Health in the PAHO region. As collaborators involved in all stages in the development of the Strategic Plan, Dr Carlos Acevedo and Dr Marco Tulio Medina have been invited to officially participate in this meeting, representing IBE and ILAE respectively. Following approval and official signing of the project by the Ministers, the Strategic Plan will be officially launched at a regional workshop, taking place in Honduras on the 21<sup>st</sup> - 23<sup>rd</sup> October. Among the participants at the workshop will be IBE President Mike Glynn; ILAE President Nico Moshé; Hanneke de Boer, representing the Global Campaign; Tarun Dua on behalf of WHO; Gary Mathern for the Institute of Medicine (IOM); Carlos Acevedo and Marco Tulio Medina. The workshop will take the first steps in rolling out the Strategic Plan throughout the entire American continent.





**Pieces**  
Thilde Mørup Christensen

## **EPILEPSY WITHOUT WORDS**

### **Golden Jubilee Photography Competition**

# **ANNOUNCING THE WINNERS !**

With a total number of entries in excess of 300, the judging panel for IBE's Golden Jubilee photography competition were faced with a very difficult task in selecting the overall winner. Some amazing photographs, some telling very personal stories, others using fantastic photographic techniques, were received from all over the world. All of the images received before the deadline on 1<sup>st</sup> May, are now available to view on the IBE website. We hope you will enjoy them and, perhaps, find some inspiration to get out your own camera!

**Pieces** by Danish photographer Thilde Mørup Christensen, pictured above, was selected by the judges to receive first prize. Voting individually, this was the highest rated photography by each member of the judging panel, making it a clear winner. I am sure you will agree with the judges that this is a very compelling image using

advanced and complex photography techniques and delivers what was requested - an image of epilepsy without words.

For this wonderful image, Thilde Mørup Christensen will receive a prize of US\$3,000.

Winner of the second prize, with a fund of US\$2,000 is **Seizure** by Anders Nilsson from Sweden. This photograph also used interesting techniques to demonstrate the feeling of epilepsy.

Given the high number of entries, it was a surprise that two images tied for third prize and will share the prize receiving US\$500 each. The winners were James Leahy from Ireland with **Fear of it All** and Kai Löffelbein from Germany with **Look**.

In the mobile phone category, the prize-winners were: Lotta Hoffback-Kaljo, Sweden (First Prize: US\$500) for **Light in**

**the Tunnel**; Sherwyn Vargas, Philippines (Second Prize: US\$300) for **My world and me** and Patricia Simpson-Green, USA (Third Prize US\$200) for **1st known Grand Mal at 60miles per hour**.

IBE would like to thank the members of the judging panel:

- Denise Chapman, Australia
- Shunglon Lai, Taiwan
- Susanne Lund, Sweden,
- Peter Murphy, Ireland,
- Simon Shorvon, UK,
- Tatsuya Tanaka, Japan
- Sam Wiebe, Canada

for their diligent consideration of all of the entries received.

Supported by UCB Pharma SA







**Previous Page:**

**Pieces** by Thilde Mørup Christensen

**This page, clockwise from top left:**

**Seizure** by Anders Nilsson

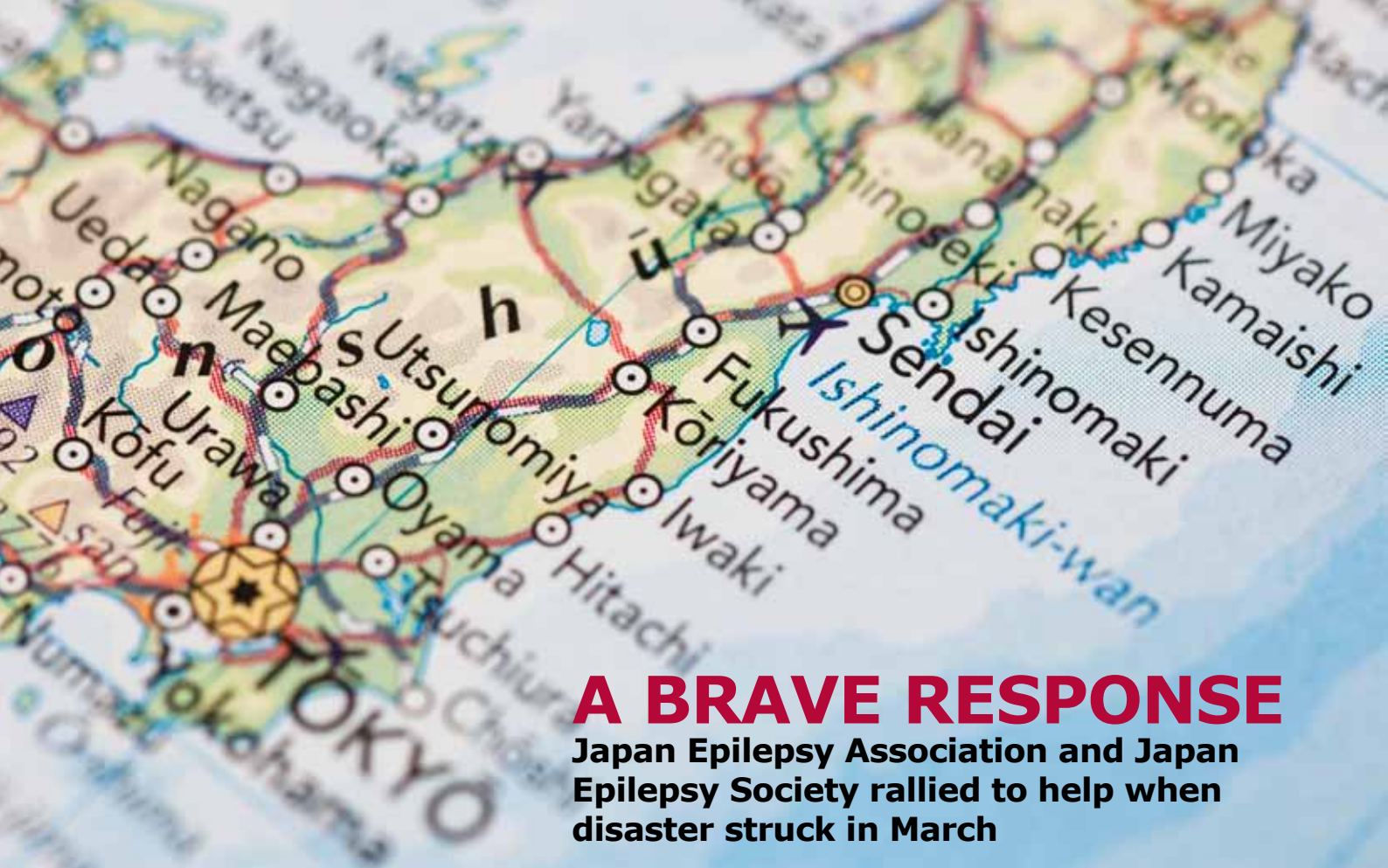
**Fear of it all** by James Leahy

**Look** by Kai Löffelbein

**My world and me** by Sherwyn Vargas

**1st known Grand Mal at 60 miles per hour** by Patricia Simpson-Green

**Light in the Tunnel** by Lotta Hoffback-Kaljo



## A BRAVE RESPONSE

Japan Epilepsy Association and Japan Epilepsy Society rallied to help when disaster struck in March



*Photos, from left: A crowded notice board at the school; a medical team sets off for the disaster area - with the special rescue pass pasted on its windscreen; a classroom is turned into a supply room and sleeping area for doctors; the school corridor serves as a waiting room for patients*

Epilepsy Hospital Bethel, an Associate Member of IBE, opened in 1992 as a private hospital specialising in epilepsy surgery and care. The centre provides a comprehensive treatment program, including diagnosis of epilepsy syndrome and seizure type, treatment programs as well as the provision of reintegration training and sheltered accommodation.

Based in Sendai Province in North Japan, the area most badly affected by the March 2011 earthquake and tsunami, the hospital faced a huge disaster following these events. In response, the Japan Epilepsy Society (ILAE chapter in Japan) and Japan Epilepsy Association (IBE member in Japan) joined forces and rallied to help. Efforts were made to contact all of the 387 members of Japan Epilepsy Association by phone, although not all were found.

An epilepsy hotline was set up to provide information and support to both persons

with epilepsy and medical professionals. When the disaster struck, many of the medical professionals caring for those affected by the disaster would have had limited knowledge about epilepsy and the hotline provided an important source of information and advice.

As a first response, medical teams from Shizuoka and Nishi-Niigata national epilepsy centres travelled north to the disaster area bringing stocks of anti-epilepsy drugs (AEDs) with them. One team stayed at the biggest shelter in the area (which had previously been a school) to provide treatment and care to persons with epilepsy who came looking for help. Another team visited other shelters announcing they were an epilepsy specialist team, that they had AEDs and could give advice. They also left written notices to let people know that there were AEDs in the school shelter and in some hospitals.

They and other epileptologists in disaster area reported back that seizure activity for a significant number of people with epilepsy was exacerbated and some people with epilepsy had convulsive status epilepticus and were transported to hospital by helicopter, because the devastation of the tsunami left a large number of people without their medication.

Japan Epilepsy Society and Shizuoka Epilepsy Center asked pharmaceutical companies to donate supplies of AEDs and these requests were generously met. However, transporting the medication to the disaster area remained a large problem. In the end, the supplies were transported to the hub-hospital by Japan Trucking Association, following a plea for help by Japan Epilepsy Associations. The supplies were then distributed to the three main hospitals in the area.

# Excellence in Journalism Awards 2011

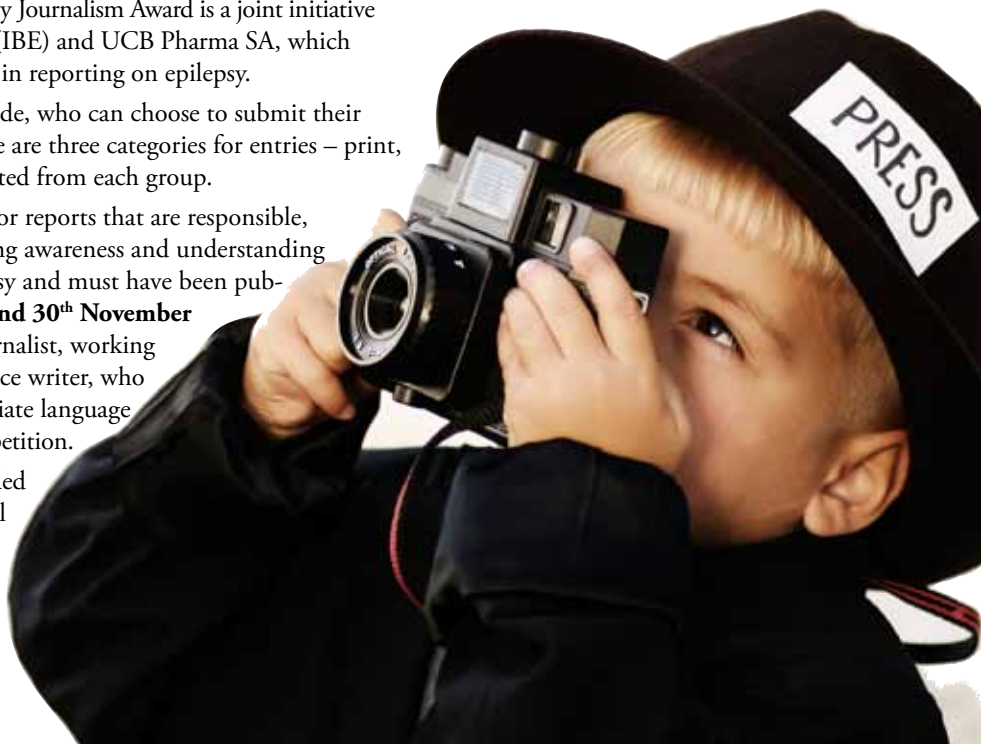
## Recognising outstanding reporting on epilepsy

Now in its 3<sup>rd</sup> year, the Excellence in Epilepsy Journalism Award is a joint initiative of the International Bureau for Epilepsy (IBE) and UCB Pharma SA, which recognises journalists who have excelled in reporting on epilepsy.

The 2011 award is open to all journalists worldwide, who can choose to submit their own work or be nominated by a third party. There are three categories for entries – print, online and broadcast, with one winner to be selected from each group.

An independent judging panel will select articles or reports that are responsible, informative, original and support the aim of raising awareness and understanding of epilepsy. Entries can be on any aspect of epilepsy and must have been published or broadcast between **30<sup>th</sup> October 2010 and 30<sup>th</sup> November 2011**. There is no time to lose! If you know a journalist, working for a newspaper, TV or radio channel, or a freelance writer, who has written or reported on epilepsy using appropriate language and tone, please encourage them to enter the competition.

A prize of €4,000 in travel vouchers will be awarded for each category. It is encouraged that these travel vouchers could be used to defray travel costs related to further journalistic research and publications about epilepsy in an international context. To find out more, visit the IBE stand at the 29<sup>th</sup> International Epilepsy Congress in Rome or visit the IBE website [www.ibe-epilepsy.org](http://www.ibe-epilepsy.org).



## Employment integration in Lombardy for people with epilepsy



**2010** was named as European Year for Fighting Poverty and Social Exclusion, providing a good opportunity to reflect on the social activities carried out in recent years by the Regional Epilepsy Center, San Paolo Hospital, Milan.

The problem of integration is one of the biggest emergencies that people with epilepsy must face. Many have difficulties finding work and integration is often a serious problem due to the risks of ac-

cidents and occupational-related disease (e.g. severe forms of drug-resistant epilepsy), but also due to the implications and social practices in the workplace, such as those related to suitability for the job, difficulty of adequately handling the issues connected to their epilepsy.

In this complex situation the Regional Epilepsy Centre has been busy in recent years in promoting projects designed to enhance and support these individuals in the workplace. The idea, thanks to employment policies and equal opportunities, sees its full realisation in legislation on the employment of people with a disability (Law 68/99), in particular the concept of 'targeted employment.'


The Regional Epilepsy Centre promoted initiation of these projects, a network approach, involving both volunteers active for years in fighting epilepsy (the Lombardy section of AICE) and various agencies, to identify different solutions to

the various problems that arise because of the disease (e.g. loneliness and exclusion, limitations arising from epilepsy therapy, etc) in order to prepare candidates to look for a more professional and competitive work environment, which is often hostile to such persons.

Special mention is due to San Paolo for outstanding support in establishing the project, with thanks to all heads of departments/services of the hospital who offered a unique contribution in the implementation of the internship. At the end of the course, six students were employed as administrative assistants, with monthly contracts. Three students their places under the convention of San Paolo, to cover a number of places reserved for people with a disability, in line with Law 68/99.

**Project implementation:** *Paola Somenzi, social worker; Ada Piazzini, neuropsychologist, Roberto Vigorelli, ex-trainee social service - all at Regional Epilepsy Centre, San Paolo Hospital, Milan. Raffaele Canger, Maria Paola Canevini.*



  
**International Bureau  
for Epilepsy**  
1961 - 2011  
50 years focussed on epilepsy

 **29<sup>th</sup> International  
Epilepsy Congress**   
**ROME 2011**  
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EPILEPSY  28<sup>th</sup> August - 1<sup>st</sup> September