

**FINAL PROGRAMME**



**12<sup>th</sup>  
European  
Conference  
on  
Epilepsy  
&  
Society**



**Porto, Portugal**  
**25<sup>th</sup> - 27<sup>th</sup> August 2010**

[www.epilepsycongress.org](http://www.epilepsycongress.org)  
[www.epilepsyandsociety.org](http://www.epilepsyandsociety.org)





## INDEX

Conference Sponsors & Exhibitors	2
Organising Committee	3
Conference Secretariat	3
Greeting from the President of IBE	4
General Conference Information	5
Social Programme	7
General Information	9
Introduction to the Programme	10
Programme at a Glance	11
Conference Programme – Wednesday 25 <sup>th</sup> August	12
Conference Programme – Thursday 26 <sup>th</sup> August	13
Conference Programme – Friday 27 <sup>th</sup> August	21

## CONFERENCE SPONSORS & EXHIBITORS

- Bial
- EPI-Apfape
- EUCARE
- International Bureau for Epilepsy
- Medtronic
- Porto Convention & Visitors Bureau
- UCB Pharma



## ORGANISING COMMITTEE

### Chair:

**Athanasios Covanis** (Greece), *EREC*

**Michael Alexa** (Austria), *EREC*

**Victoria Dimech** (Malta), *EREC*

**Aisling Farrell** (Ireland), *EREC*

**José Lopes Lima** (Portugal), *EPI*

**Janet Mifsud** (Malta), *EREC*

**Nelson Ruão** (Portugal), *EPI*

**Seppo Sarkkula** (Finland), *EREC*

## CONFERENCE SECRETARIAT

12<sup>th</sup> European Conference on Epilepsy & Society  
7 Priory Hall  
Stillorgan  
Dublin 18  
Ireland  
Tel : +353 1 2056720  
Fax : +353 1 2056156  
Email : [porto@epilepsycongress.org](mailto:porto@epilepsycongress.org)  
[www.epilepsyandsociety.org](http://www.epilepsyandsociety.org)





## GREETING FROM THE PRESIDENT OF IBE

Dear Friends,

We are coming together this year in Porto for what promises to be a really interesting conference. This year's programme is full of exciting and informative sessions aimed at providing information and promoting dialogue on a variety of issues that are affecting people with epilepsy living all over Europe.

The programme this year is based on topics suggested by IBE members and it is important to note that the majority of speakers were also suggested by IBE European member associations. There is no doubt that all of the speakers will make a significant contribution to the discussions that will ensue over the course of the conference.

The theme of the European Conference on Epilepsy and Society this year is "Epilepsy... so what?" which analyses different aspects of living with epilepsy. As IBE President, I am proud to be part of this meeting in particular because the main objective of the conference is to reduce the stigma by discussing issues associated with epilepsy. Stigma can be deeply hurtful, isolating and can be used to exclude and marginalise people. It is necessary to confront biased social attitudes in order to reduce the discrimination and stigma of people who are living with epilepsy. That this why the eradication of epilepsy-related stigma is something that the International Bureau for Epilepsy is committed to and I have listed it among the urgent matters I would like to address during my time as IBE President.

I wish you all a very pleasant few days in Porto. I hope you enjoy your time here and I look forward to meeting all of you over the course of the conference.

Best wishes,



**Mike Glynn**  
President  
International Bureau for Epilepsy



## GENERAL CONFERENCE INFORMATION

The venue for the 12<sup>th</sup> European Conference on Epilepsy and Society is the Sheraton Hotel Porto. This hotel is a modern wonder of marble, wood, steel and glass, situated in the heart of Porto. Its central location means bustling business, shopping and entertainment districts are just a short stroll for delegates.

### Sheraton Porto

Rua Tenente Valadim 146  
4100-476 Porto  
Portugal  
<http://www.sheratonporto.com/>

The hotel is located at a 10 minute walk from the metro station “Francos” (metro line E) and it is directly connected to the airport.



### Registration Area and Name Badges

The Delegate Registration Area is located at the Sheraton Hotel Porto on the SL floor. Delegates must register at the Registration Desk and receive their conference badges and packs before being allowed to enter the conference.

The Registration Desk will be open at the following times:

Wednesday 25 <sup>th</sup> August	: 12.00-17.00
Thursday 26 <sup>th</sup> August	: 07.00-17.00
Friday 27 <sup>th</sup> August	: 08.00-16.00

Only delegates wearing conference badges will be allowed access to session rooms. Please note that there will be a charge for replacing lost badges.



## GENERAL CONFERENCE INFORMATION

### Speakers' Presentations

All Main Session speakers are requested to hand their presentations to the Conference Secretariat at the Registration Desk at least 30 minutes before their presentations are due to begin.

### Posters

Posters will be displayed in the Hall outside the main session room. Those delegates who have brought posters to display during the conference should contact the Conference Secretariat at the Registration Desk for instructions and assistance in hanging their posters.

On Friday 27<sup>th</sup> August 14.00-15.00 delegates will also have an opportunity to present their posters. Certificates will be provided for Poster presenters.

### Exhibition

An exhibition will run in conjunction with the conference. This is an integral part of the conference, offering delegates the opportunity to learn about products and services. Exhibition stands will be allocated in the coffee break area in the Hall outside the main session room.

### Lunch and Coffee Breaks

Coffee Breaks will be served in the Hall outside the main session room, where the exhibition stands and posters are located.

Lunches will be served in the Hall outside the main session room at the following times:

Thursday 26 <sup>th</sup> August	12.15-13.30
Friday 27 <sup>th</sup> August	13.15-14.00

### Insurance

It is recommended that participants arrange personal health, accident and travel insurance. The conference organiser will not accept liability for personal injury or loss of/ damage to property or belongings of participants or accompanying persons, before, during or following the conference, tours or their stay in Porto.



## SOCIAL PROGRAMME

### Tours

A full selection of guided tours of Porto and the surrounding areas may be booked at the Information desk in the Exhibition area during the Conference.

### Opening Ceremony



#### Wednesday 25<sup>th</sup> August 19.00

The Opening Ceremony of the 12<sup>th</sup> ECES will take place in Santa Casa da Misericórdia do Porto on Wednesday 25<sup>th</sup> August at 19.00.

The Opening Ceremony will be followed by a small welcome reception hosted by EPI-Apfape, the IBE member association in Portugal.

For directions to the Santa Casa da Misericórdia do Porto, please ask at the Registration Desk.



### Karaoke Evening

#### Wednesday 25<sup>th</sup> August 20.30

The Karaoke Evening venue is Triplex bar located 1km (8 minute-walk) from the Sheraton Hotel Porto.

An entrance fee of €5.00 will be charged at the door, which will be offset against drinks and food purchased during the evening.



## SOCIAL PROGRAMME

### Social Evening



#### Thursday 26<sup>th</sup> August at 20.00

The Social Evening will be held on Thursday 26<sup>th</sup> August in a very special venue Três Séculos situated within Taylor's Port lodge, one of the world-famous port wine cellars.

In a unique setting on a hill on the south bank of the River Douro overlooking Porto and surrounded by leafy quarters, Três Séculos' elegant interiors lie within beautiful natural gardens that allow the visitor to experience Porto's charismatic atmosphere and beauty.

Tickets for the Social Evening cost €35 each. The ticket price includes:

- Welcome Port Reception
- Guided tour of Taylors Porto Warehouse
- Seated Dinner

Tickets for the social evening may be purchased at the Registration Desk. As attendance numbers at the Social Evening are restricted by the venue, please ensure you get your tickets early to avoid disappointment!



## GENERAL INFORMATION

### Porto

The social and trade relations that Porto has developed over time with Northern Europe, the Mediterranean, Africa, Brazil, India and Japan, are reflected in the city's rich cultural heritage. From the remains of Visigoth and Celtic villages, Roman roads, bridges and Castros to Romanesque and Gothic churches and cathedrals built during the Medieval Age, centuries of mankind-built heritage are to be discovered in and around Porto.

The recognition of Porto by UNESCO in 1996 as a World Heritage City is undoubtedly a tribute to its wealth of over two thousand years of history. This nomination reflects the commitment of the Municipality and Central Government since the early 1980's with the urban regeneration projects that encompass both social and cultural interventions. At the beginning of a new Millennium, Porto is proud to present a Historic Centre consisting of over 150 classified monuments.

Porto is Portugal's second-largest city, with 300 000 inhabitants, and the heart of an area of great vitality, ideal gateway to the undiscovered North of Portugal.

The friendly welcoming nature of the Portuguese people, highly professional and cost-effective services are a guarantee of a successful event and will give you something to remember in the future.

### Credit Cards & ATMs

Most hotels, restaurants, shops and taxis accept major credit cards; however, it is recommended that visitors also carry small amounts of cash at all times. ATMs are widely available throughout the city of Porto.

### Currency

The currency in Portugal is the Euro.

### Electricity

Portugal, like most other European countries, has 220 volt current and uses 2-pin plugs. Visitors from the UK and Ireland will require an adaptor plug for appliances, from 3-pin to 2-pin. Visitors from North America will require a transformer plug in order to use 110/125V appliances.

### Emergencies & Medical Care

To contact the police, fire department or medical response in an emergency, dial 112. Emergency medical care is supplied by the municipal authorities. Venue and hotel staff members can direct guests to local emergency centres, hospitals or dental clinics.

The E111 form is no longer valid. Delegates will need a European Health Insurance Card (EHIC) to receive necessary healthcare during a visit to a European Economic Area (EEA) country or Switzerland.

### Language

The language in Porto is Portuguese. The official language of the conference is English.

### Transport

The Metro in Porto operates on five different lines, which are conveniently marked with different letters (A through to E) and by different colours. The metro covers virtually the entire city as well as some neighbouring towns. In addition, an extensive bus network serves the city and suburbs of Porto.

Taxis are fairly inexpensive and very easy to find. You can either book them in advance or hail one off the street.



## INTRODUCTION TO THE PROGRAMME

Dear Friends,

On behalf of the European Regional Executive Committee and the Organising Committee, it is my pleasure to welcome you to the beautiful city of Porto for the 12<sup>th</sup> European Conference Epilepsy and Society, August 25-27, 2010. Over the past two years the Organising Committee has worked hard to create a programme based on the latest developments in the field of epilepsy. The theme of the conference is "Epilepsy... so what?".

Distinguished speakers will come together to exchange ideas and experiences on new developments in epilepsy treatment, associated cognitive dysfunction and the psychosocial implications that derive from this common brain disorder. The programme includes plenary sessions, discussion groups, parallel sessions and a Youth Session. Special emphasis is being placed on Posters during the 12<sup>th</sup> ECES and certificates will be provided for poster presenters.

In addition, we have two great social events. The opening ceremony will take place in Santa Casa da Misericórdia, a special venue in Porto's historical centre, followed by a Karaoke Evening in the Triplex bar in the proximity of the Sheraton Hotel Porto.

For the Social Evening we have selected one of the most beautiful venues in Porto, where delegates will enjoy a Port wine reception followed by a dinner overlooking the city. The view is breathtaking! Tickets for the Social Evening can be purchased at the registration desk.

We look forward to welcoming you to the charismatic city of Porto for what is going to be an excellent gathering of wonderful people. In this way we believe we will not only increase our knowledge and understanding of epilepsy but we will also fulfil the goals of the International Bureau for Epilepsy.

Best wishes,



**Athanasios Covanis**

Chair IBE European Regional Committee



**PROGRAMME AT A GLANCE**

<b>Wednesday 25<sup>th</sup> August</b>		<b>Thursday 26<sup>th</sup> August</b>	<b>Friday 27<sup>th</sup> August</b>
	Global Campaign Against Epilepsy - Launch of the European Report 08.00-9.00	Global Campaign Against Epilepsy - Launch of the European Report 08.00-9.00	UCB Breakfast Session Inspiring Voices of people Living with Epilepsy 08.00-9.15
	Epilepsy brain and mind 09.00-09.30	Epilepsy brain and mind 09.00-09.30	Photosensitivity and epilepsies 09.15-10.15
	Epilepsy and cognition 09.30-10.00	Epilepsy and cognition 09.30-10.00	Coffee Break
	Coffee Break	Coffee Break	
	Epilepsies, AEDs and health issues 10.30-11.00	Epilepsies, AEDs and health issues 10.30-11.00	Influencing Policy 10.45-11.45
	Ethics in epilepsy 11.00-11.30	Ethics in epilepsy 11.00-11.30	EUCARE Session More concerted action for more change! 11.45-13.15
	Epilepsy is more a social condition than a medical one 11.30-12.15	Epilepsy is more a social condition than a medical one 11.30-12.15	
	Lunch	Lunch	Lunch
<b>IBE European Committee Meeting 13.00-15.00</b>	Brain Stimulation 13.30-14.00	Brain Stimulation 13.30-14.00	
	Driving and Epilepsy Epilepsy in the family What is life like for people living with epilepsy A chance for a better life (Mainstreaming Project) 14.00-15.30	Driving and Epilepsy Epilepsy in the family What is life like for people living with epilepsy A chance for a better life (Mainstreaming Project) 14.00-15.30	Workshop EPI A Comunicação Social e a Epilepsia 14.00-15.00
	Coffee Break	Coffee Break	Training for success Working with politicians Are smoking, caffeine and alcohol risk factors for seizures? 15.00-16.00
	Group A: School and work Emergency cards and warning devices 16.00-16.30	Group A: School and work Emergency cards and warning devices 16.00-16.30	Youth session: sex, drugs and lifestyle choices 16.00-17.00
	Group B: School and work Emergency cards and warning devices 16.30-17.00	Group B: School and work Emergency cards and warning devices 16.30-17.00	
	Best practice in twinning of IBE Members Personal development Opportunities 16.00-16.30	Best practice in twinning of IBE Members Personal development Opportunities 16.00-16.30	Concluding Session 17.00-17.15
Opening Ceremony 19.00-20.00			
<b>Karaoke Evening 20.30-late</b>	<b>Social Evening 20.00-late</b>	<b>Social Evening 20.00-late</b>	



## CONFERENCE PROGRAMME - WEDNESDAY 25<sup>TH</sup> AUGUST

### “Epilepsy... so what?”

The 12<sup>th</sup> ECES will take place from Wednesday 25<sup>th</sup> August to Friday 27<sup>th</sup> August 2010. The theme of the conference is “Epilepsy... so what?” which analyses different aspects of living with epilepsy. The main objective of this programme is to reduce stigma by discussing issues associated with epilepsy. In addition, the 12<sup>th</sup> ECES programme is mainly based on topics suggested by members of the International Bureau for Epilepsy (IBE). The majority of speakers were also suggested by IBE European member associations. During the conference, delegates will also have a lot of opportunities to socialise and participate in discussion groups, parallel sessions and other programmed activities.

### 13.00 - 15.00 IBE European Committee Meeting

Ariane Room

Annual meeting of IBE European Committee. Representatives from all IBE European member associations are invited to participate.

### 19.00 - 20.00 Opening Ceremony

Santa Casa da Misericórdia do Porto

The Opening Ceremony of the 12<sup>th</sup> ECES will take place in Santa Casa da Misericórdia do Porto and followed by a small welcome reception hosted by EPI-Apfape, the IBE member association in Portugal.

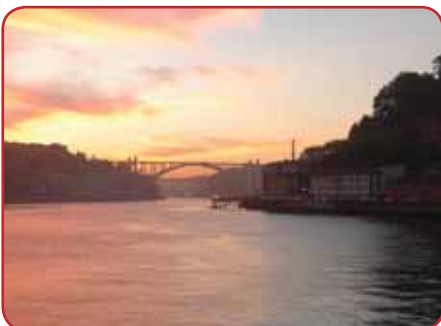
For directions to this venue please contact the Information Desk.

### 20.30 Karaoke Evening

Triplex Bar

The Karaoke Evening venue is Triplex bar located 1km (8 minute-walk) from the conference venue.

Triplex is one of the finest bars in Porto, a combo bar-restaurant-terrace, modern and cosmopolitan, located in a whitewashed house dating from the early 20<sup>th</sup> century. For more information on this venue, please visit [www.triplex.com.pt](http://www.triplex.com.pt)





## CONFERENCE PROGRAMME - THURSDAY 26<sup>TH</sup> AUGUST

**08.00 - 09.00**

Global Campaign Against Epilepsy  
**Launch of the European Report**

Ariane Room

### Launch of the European Report

One of the most significant events at the 12<sup>th</sup> European Conference on Epilepsy and Society in Porto will be the launch of the European Report on Epilepsy of the Global Campaign Against Epilepsy. This long-awaited, important report, which is being published by the WHO, will be officially launched by Dr Matt Muijen, WHO Regional Advisor for Mental Health.

The report will bring together, for the first time, all available evidence from the region on the epidemiology, etiology and management of epilepsy and will be a valuable tool for those working for change at national level.

**09.00 - 09.30**

Main Session  
**Epilepsy brain and mind**  
Chair: Athanasios Covanis, Greece

Apollo Room

Co-Chair: José Lopes Lima, Portugal

### Epilepsy brain and mind - *Niall Pender, Ireland*

Epilepsy has been associated with changes in cognitive and psychological functioning which can reflect underlying changes to the brain, the direct effects of seizures on cognitive functions and the possible side-effects of anti-convulsant medication. Certain forms of epilepsy can carry a greater risk of cognitive dysfunction such as medial-temporal sclerosis. Cognitive and emotional difficulties can be disabling for sufferers and their families and can also have a significant impact on both educational and occupational attainments. Epilepsy can also be associated with changes in emotional and psychological functioning including depression, anxiety and social withdrawal. The current talk will examine the nature of psychological difficulties in epilepsy focusing on the assessment and treatment of these conditions.

**09.30 - 10.00**

Main Session  
**Epilepsy and cognition**  
Chair: Athanasios Covanis, Greece

Apollo Room

Co-Chair: José Lopes Lima, Portugal

### Epilepsy and cognition - *Melissa Filippini, Italy*

Epilepsy is a complex syndrome and cognitive aspects have to be considered in order to define diagnosis and provide a rehabilitative project and prognosis. Cognition in epilepsy has to be studied considering a multi factorial model, including also the age of onset, the frequency of seizures and/or epileptiform discharges. Epilepsy can affect the development of neural networks subserving cognitive functions during critical periods of growing up. Rehabilitation can help to overwhelm these effects.

**10.00 - 10.30**

**Coffee Break**

Hall outside Apollo Room



## CONFERENCE PROGRAMME - THURSDAY 26<sup>TH</sup> AUGUST

10.30 - 11.00

Main Session

### **Epilepsies, AEDs and health issues**

Chair: Athanasios Covanis, Greece

Apollo Room

Co-Chair: José Lopes Lima, Portugal

#### **Epilepsies, AEDs and health issues** - *Janet Mifsud, Malta*

Epilepsy, which affects as many as 6 million people in Europe, is a heterogeneous chronic disorder characterized by recurrent seizures, which differ in nature, types of seizures, age at onset and aetiology. No single antiepileptic drug (AED) is appropriate in all types of epilepsies since the causes of epilepsy are extremely diverse, encompassing various heterogeneous genetic and developmental defects and infective, traumatic, neoplastic, and degenerative disease processes.

In addition, even though a large number of antiepileptic drugs (AEDs) that suppress or prevent seizures are now available, so far, drug therapy available will only control the onset of seizures and there are no pharmacological treatments that cure epilepsy or modify the detrimental course of the disorder. The selection of the appropriate AED is also made on a variety of specific factors, such as age, gender, underlying physiological conditions and possible drug interactions. The prognosis and quality of life of a person with epilepsy varies considerably. In addition, about 30% of patients remain resistant to drug treatment. This has major implications not only for other health issues, but also for independent living, education and employment, mobility, and personal relationships.

11.00 - 11.30

Main Session

### **Ethics in epilepsy**

Chair: Athanasios Covanis, Greece

Apollo Room

Co-Chair: José Lopes Lima, Portugal

#### **Ethics in epilepsy** - *Ley Sander, UK*

Ethics are the set of moral values that govern the interactions of oneself with others, with society and with the surroundings encompassing all spheres of life. In other words, ethics concerns the duties, obligations, and taking the right actions in our dealing with others.

Epilepsy is a multi-faceted condition which affects many domains of people's life. As such there are many aspects to ethics in epilepsy. These involve the relations between people with the condition and their carers, family, peer group, health providers, and society as a whole.

Treatment issues, choice of treatments, decision to treat or not to treat, consent and assent for procedures and investigations all raise ethical issues but these may be particularly difficult when it involves those people in whom there are issues of mental capability. In this lecture, ethical issues that concern epilepsy care delivery and the relations that they create will be reviewed and discussed.



## CONFERENCE PROGRAMME - THURSDAY 26<sup>TH</sup> AUGUST

11.30 - 12.15

Main Session

### **Epilepsy is more a social condition than a medical one**

Chair: Janet Mifsud, Malta

Apollo Room

Co-Chair: Aisling Farrell, Ireland

#### **Social aspects** - *Victoria Dimech, Malta*

During this session we will discuss some of the various social impacts PWE and their families have to deal with. We will look into misunderstandings about epilepsy, labelling, stigma, discrimination etc. and what effect this can have on the quality of life, life choices, employment. Often times these social problems further hinder a person's achievement in life because their emotional and social development is affected.

#### **Medical aspects** - *José Lopes Lima, Portugal*

These issues need to be addressed together with the medical aspects of the condition. Epilepsy requires medical intervention to be detected and identified, either clinically or with the help of complementary laboratory medical studies. Many of them have associated medical problems that must be handled together with the epilepsy: mental retardation, hemiparesis, progressive dementia, etc. depending on the common ethiology. Although the person with epilepsy has to be considered and managed as an individual person, with all the personal and social implications, as any other medical chronic condition, the main aim of the treatment is still the medical control of all the seizures generally by drug treatment or, eventually, by surgical approach.



**CONFERENCE PROGRAMME - THURSDAY 26<sup>TH</sup> AUGUST****12.15 - 13.30****Lunch**

Hall outside Apollo Room

**13.30-14.00**

Main Session

**Brain Stimulation**

Chair: Athanasios Covanis, Greece

Apollo Room

**14.00 - 15.30****Discussion Group**

Chair: Seppo Sarkkula, Finland

Apollo Room

**Driving and epilepsy** - *Mike Glynn, Ireland*

The EU's Directive on driving regulations for people with epilepsy (Commission Directive 2009/112/EC) is due to come in to force in each of the European Union member states on or before the 29<sup>th</sup> August 2010. This date nicely coincides with the finish of our 12<sup>th</sup> European Conference on Epilepsy and Society in Porto. It would be nice to think everything would be done in an orderly fashion and that by the time we were leaving another great ECES everything would be tied down and there would be in place a uniform system for dealing with first seizures and diagnosed epilepsy for all European citizens for both cars, vans, motorcycles and for large vehicles such as buses, trucks and HGVs.

Indications are that many member states have not yet made any moves to bring the new Directive into law in their countries. This presentation will concentrate on the issues for IBE member associations in ensuring that the new regulations are enacted in their countries and, afterwards, operated correctly so that people with epilepsy get the fair treatment they deserve in regards to their opportunities to drive. Some member states may seek to avail of a facility to make their regulations tougher than the Directive's recommendations but IBE members should seek to resist this as it is probably unsustainable due to pressure from EU citizens and groups for all people to have equal treatment under the law right across Europe.

**Epilepsy in the family** - *An De Cock, Belgium*

When epilepsy is diagnosed in a family member it will feel as though a bomb has exploded. The fact that epilepsy is more than just the occurrence of seizures quickly becomes apparent. Not only the person with epilepsy but the entire family is affected. It seems like a mourning process. Learning to deal with the epilepsy, being dependent on others are all things that must be dealt with, whatever form the seizures may come in.

During the first few months after a diagnosis of epilepsy, the support of a social network is essential. Some people feel they need to learn about epilepsy. Other people may feel the need to talk about their feelings and others still will concentrate on caring for their children and will want to be actively involved. The discussion of anxiety surrounding seizures, the expression of concern about the future, receiving positive support and having the feeling that people are there to listen to your experience are all themes which are important after the diagnosis. With raising a child or adolescent with epilepsy overprotection can lead to a loss of independence and personality. Parents are often scared to set rules and boundaries out of fear of triggering a seizure. This is perfectly normal, yet often requires guidance with professionals to search for a balance between safety and development of the child or adolescent. One can conclude that the treatment of epilepsy is not only medical in nature but must also address the impact epilepsy has on the family.



## CONFERENCE PROGRAMME - THURSDAY 26<sup>TH</sup> AUGUST

### **What is life like for people living with epilepsy?** - *Per Olsen, Denmark*

With the aid of The Danish National Centre for Social Research, The Danish Epilepsy Association (DEA) has carried out four scientific surveys of living conditions of DEA members. The surveys are:

- Living conditions of adults with epilepsy (2007)
- Living conditions of children with epilepsy (2008)
- Living conditions of adolescents with epilepsy (2009)
- Partners to people with epilepsy (2009)

The surveys contain very valuable information which we at DEA can use in both our political work and in estimating present and future needs of PWE.

We believe that it is extremely important that our political work is based on science and not feelings. Our surveys have been carried out with the exact purpose of finding out what life is like for people suffering from epilepsy and how our members perceive and rank the work of DEA.

Highlights will be presented and discussed

### **A chance for a better life (Mainstreaming Project)** - *Sam Whitmore, Scotland*

Epilepsy Connections' Mainstreaming Project: Connecting People to Opportunities

Based in Glasgow, Scotland's biggest city, Epilepsy Connections' Mainstreaming Project provides a second chance to people with epilepsy whose choices in life have been compromised by their condition and who are seeking a new direction.

Unique of its kind in Scotland, the Mainstreaming Project places epilepsy needs at the centre of a programme of activities designed to build skills and confidence. Taking part in the project gives people with epilepsy the knowledge, skills and self-confidence they need to live well with epilepsy.

The project's key objectives are to support people with epilepsy to:

- broaden their horizons and take steps towards a new life that includes education, training, paid or voluntary work and new interests
- improve their wellbeing, achieve greater levels of independence and self-determination, develop interpersonal skills and increase self-confidence and self-esteem.

Our presentation will demonstrate how we meet these objectives and how the Mainstreaming Project supports people with epilepsy to make positive, lasting changes to their lives.

**15.30 - 16.00**

**Coffee Break**

*Hall outside Apollo Room*



## CONFERENCE PROGRAMME - THURSDAY 26<sup>TH</sup> AUGUST

16.00 - 16.30

Parallel Session  
**Group A**  
Chair: Nelson Ruão, Portugal

Apollo Room

### **School and work** – *Sofia Neves, Portugal*

Given that epilepsy affects mostly children and young people and that education professionals know very little about this condition, it seems of utmost importance that EPI-APFAPE continues to develop initiatives of awareness. In this presentation, we want to share with other European associations our experience of intervention in schools, as well as teaching materials support.

In addition, this presentation will focus on our training experience in schools with the aim of promoting the integration of pupils with epilepsy and how the awareness of education professionals can promote academic potential and career guidance to each student taking into account the type of epilepsy and their seizure frequency.

### **Emergency cards and warning devices** – *Aisling Farrell, Ireland*

This is an opportunity for IBE members to come together and discuss the different types of emergency cards and warning devices that are available in each of their countries. Issues to be discussed are: do emergency cards work and what kind of systems are in place to access the information on the emergency card? What types are available, what information is to be included on the emergency cards? Does having an emergency card reduce anxiety when out in the community? It is also an opportunity to discuss different types of warning devices that are available such as alarms.

16.00 - 16.30

Parallel Session  
**Group B**  
Chair: Andriani Ioannidou, Greece

Ariane Room

### **Best practice in twinning of IBE Members** – *Seppo Sarkkula*

We have had some contact with countries where the question was: "How to start a new Epilepsy Association". I am also telling how successful the cooperation with those countries and associations has been and how to become IBE Member.

My purpose is also to wake up/inspire discussion about how could we possibly find good or better methods in the cooperation with Epilepsy Associations.

### **Personal development opportunities** – *Michael Alexa*

What do Agatha Christie, Leonardo da Vinci, Theodore Roosevelt, Sir Isaac Newton and Prince have in common? They all had - like the most of you - including myself had epilepsy. But all those famous people that I've mentioned have one thing in common - they NEVER gave up! They've had their goals and continued to reach them!

That's something that I can only advise yourself to do too - set yourself your own goals and do anything to reach them - I'm doing it - that's for sure. You're deciding where your road is leading you to! There are many different tracks you can choose from - girlfriend and children, career, getting famous - why not - look at Prince!!! So believe in yourself - If you really want to do something, you can do it! Epilepsy is just one part of your life!



## CONFERENCE PROGRAMME - THURSDAY 26<sup>TH</sup> AUGUST

16.30 - 17.00

Parallel Session  
**Group A**  
 Chair: Nelson Ruão, Portugal

Ariane Room

### **School and work** – *Sofia Neves, Portugal*

Given that epilepsy affects mostly children and young people and that education professionals know very little about this condition, it seems of utmost importance that EPI-APFAPE continues to develop initiatives of awareness. In this presentation, we want to share with other European associations our experience of intervention in schools, as well as teaching materials support.

In addition, this presentation will focus on our training experience in schools with the aim of promoting the integration of pupils with epilepsy and how the awareness of education professionals can promote academic potential and career guidance to each student taking into account the type of epilepsy and their seizure frequency.

### **Emergency cards and warning devices** – *Aisling Farrell, Ireland*

This is an opportunity for IBE members to come together and discuss the different types of emergency cards and warning devices that are available in each of their countries. Issues to be discussed are: do emergency cards work and what kind of systems are in place to access the information on the emergency card? What types are available, what information is to be included on the emergency cards? Does having an emergency card reduce anxiety when out in the community? It is also an opportunity to discuss different types of warning devices that are available such as alarms.

16.30 - 17.00

Parallel Session  
**Group B**  
 Chair: Andriani Ioannidou, Greece

Apollo Room

### **Best practice in twinning of IBE Members** – *Seppo Sarkkula*

We have had some contact with countries where the question was: "How to start a new Epilepsy Association". I am also telling how successful the cooperation with those countries and associations has been and how to become IBE Member.

My purpose is also to wake up/inspire discussion about how could we possibly find good or better methods in the cooperation with Epilepsy Associations.

### **Personal development opportunities** – *Michael Alexa*

What do Agatha Christie, Leonardo da Vinci, Theodore Roosevelt, Sir Isaac Newton and Prince have in common? They all had - like the most of you - including myself had epilepsy. But all those famous people that I've mentioned have one thing in common - they NEVER gave up! They've had their goals and continued to reach them!

That's something that I can only advise yourself to do too - set yourself your own goals and do anything to reach them - I'm doing it - that's for sure. You're deciding where your road is leading you to! There are many different tracks you can choose from - girlfriend and children, career, getting famous - why not - look at Prince!!! So believe in yourself - If you really want to do something, you can do it! Epilepsy is just one part of your life!



## CONFERENCE PROGRAMME - THURSDAY 26<sup>TH</sup> AUGUST

20.00

Social Evening

Caves Três Séculos

The Social Evening will be held in a very special venue **Três Séculos** situated within Taylor's Port lodge, one of the world-famous port wine cellars.

In a unique setting on a hill on the south bank of the River Douro overlooking Porto and surrounded by leafy quarters, Três Séculos' elegant interiors lie within beautiful natural gardens that allow the visitor to experience Porto's charismatic atmosphere and beauty.

The ticket price includes:

- Welcome Port Reception
- Guided tour of Taylors Porto Warehouse
- Seated Dinner

Tickets for the Social Evening are €35 each and may be purchased ask the Registration Desk.





## CONFERENCE PROGRAMME - FRIDAY 27<sup>TH</sup> AUGUST

08.00 – 09.15

UCB Breakfast Session

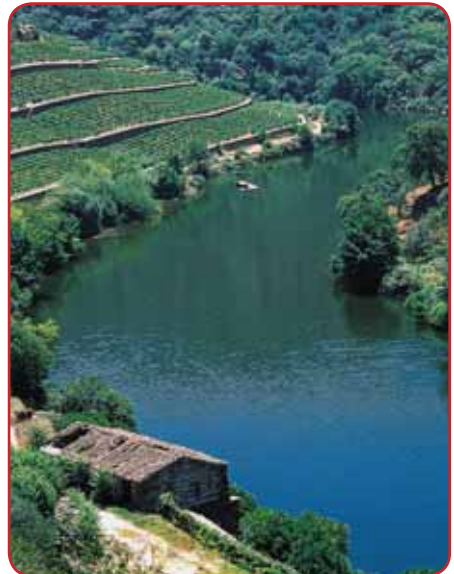
Ariane Room

**Inspiring Voices of people Living with Epilepsy**

UCB is a biopharmaceutical company based in Brussels, that is dedicated to the research, development and commercialization of innovative medicines with a focus on the fields of central nervous system and immunology.

UCB is committed to enhancing the lives of people with epilepsy, their families and carers and is working to create greater awareness and understanding of epilepsy.

The UCB Breakfast Seminar at the 12<sup>th</sup> European Congress of Epilepsy and Society is entitled '*The Inspiring Voices of People Living with Epilepsy*'. Three people will share their personal experiences of epilepsy. By sharing real life situations it is our hope that encouragement and motivation can be provided to others living with epilepsy. The sharing of personal stories with epilepsy will be followed by a facilitated and interactive question and answer session with the audience.





## CONFERENCE PROGRAMME - FRIDAY 27<sup>TH</sup> AUGUST

09.15 - 10.15

Main Session  
**Photosensitive seizures and epilepsies**  
Chair: Ley Sander, UK

Apollo Room

### **Photosensitive seizures and epilepsies** – *Athanasios Covanis, Greece*

Photosensitivity is sensitivity to flickering light source or pattern and is expressed in the EEG as a generalized spike and wave discharge and clinically by seizures most commonly tonic-clonic, myoclonic and absences. Other phenomena such as impairment of consciousness and/or pleasurable feelings do occur.

Photosensitive epilepsy occurs in 5 to 10% of young people with epilepsy. Examples of generalized idiopathic syndromes are: childhood and juvenile absence epilepsy, juvenile myoclonic epilepsy, eyelid myoclonia and absences, generalized tonic/clonic seizures only (on awakening) and some myoclonic syndromes in infancy and childhood.

The treatment of photosensitivity is dependent upon the avoidance of the provocative stimulus and/or antiepileptic drugs. The protective and avoidance methods are likely to be successful in the pure photosensitive epilepsies. Conditioning methods have been less popular. The choice of each protective measure will depend on the type of stimulus, the environment in which the person has to live and work the frequency of seizures and the type of epilepsy syndrome.

In the vast majority of patients with epilepsy and photosensitivity the use of AEDs is necessary. By far the most successful AED therapy has been sodium valproate with seizure free monotherapy results ranging from 67 to 95% in different epilepsy syndromes. Newer AEDs with a broad clinical profile such as Levetiracetam, Lamotrigine, Topiramate, Zonisamide and Lacosamide do suppress generalized spike and wave discharges. These drugs may be an alternative for those patients with troublesome VPA adverse events. However their efficacy on photosensitivity should match the excellent risk/benefit ratio existing for VPA. There is not particular age at which photosensitivity disappears.

### **Prevention of photosensitive seizures** – *Graham Harding, UK*

Photosensitive epilepsy is a relatively rare condition (1/4000) but affects more than 200,000 people in the EU.

The most common precipitating factor is television. Over sixty per cent of patients have their first seizure watching TV. The most common type of seizure is a tonic-clonic convulsion, occurring in 79 per cent of patients.

The standard TV system in Europe is PAL. The frequency of the mains current is 50 Hz CRT so televisions show this frequency and also a line frequency of the alternate lines of 25 Hz. The frame rate, i.e., the number of pictures per second is 25... These figures contrast with the NTSC system used in the USA where the mains frequency is 60 Hz with a 30 Hz line frequency and a frame rate of 30.

Most patients are sensitive between 16 and 20 flashes per second (fps), less than 3 per cent of patients are sensitive at 3 fps, and 4 per cent at 65 fps or above. In general patients are only sensitive to binocular stimulation, thus covering one eye is a good preventative measure for photosensitive patients.



## CONFERENCE PROGRAMME - FRIDAY 27<sup>TH</sup> AUGUST

Long wavelength red flicker is peculiarly provocative, seen in the Pokemon incident in 1997 where 4 seconds of red/blue reversing frames precipitated 685 hospital admissions. Of these 560 patients experienced confirmed seizures. Seventy-six per cent had no previous history of epilepsy, suggesting that although known photosensitive epilepsy is relatively rare, there might be four times as many individuals in the population who are photosensitive but who have not yet had a seizure (Harding 1998).

High contrast patterns can also be provocative, patients being most sensitive at a spatial frequency around 2 to 3 cycles per degree.

From this information the UK adopted restrictions on flashing images and repetitive patterns. Flashes were restricted to a maximum of three per second or the screen area of the flashes had to be less than 25 per cent, or the contrast to be less than 20 candelas per square metre. Patterns were restricted to five pairs of bars in any orientation unless the contrast was less than 20 candelas per metre squared, or if the pattern was stationary the area of the screen had to be less than 40 per cent and if it was oscillating or reversing the area had to be less than 25 per cent. Flashes of saturated red were not allowed irrespective of luminance. Similar guidelines on flashing have been contained in the International Telecommunications Union's Recommendation. In the USA guidelines also restrict computer games, videos and public displays. Similar guidelines restricting television broadcasts are applied in Japan. It is clear from both anecdotal and scientific studies that broadcast guidelines reduce the number of reported seizures by more than 70%.

Modern computer-based checking systems allow real-time on-line screening of material prior to transmission. Whatever the method of presentation of the television broadcast material, whether it is CRT tube, plasma screen or LCD screen, this does not affect the dangers of inappropriate material being broadcast.

**10.15 - 10.45**

**Coffee Break**

*Hall outside Apollo Room*





**CONFERENCE PROGRAMME - FRIDAY 27<sup>TH</sup> AUGUST**

**10.45 - 11.45**

Main Session  
**Influencing policy**  
 Chair: Mike Glynn, Ireland

Apollo Room

Co-Chair: Athanasios Covanis, Greece

**The role of the EU in providing support for people with epilepsy** – *Gay Mitchell, Ireland*

My speech will concentrate on what steps the European Union can take to help those with epilepsy. Healthcare is, under the principle of subsidiarity, a competence of member states, but there is scope for cooperation and sharing of best practice among those states.

I will look at how the Parliament can promote this through initiatives like the Disability Intergroup of which I am an active member, and the Working Group on Human Dignity of which I am President. I will talk about a draft motion for a resolution that I hope to sponsor in the Parliament, picking up where former MEP John Bowis left off. Such actions can keep issues such as epilepsy on the agenda and ensure that the Commissioner for Health is doing all within his power to promote Europe-wide solutions to problems that sufferers may face. It also helps to keep the issue on the agenda of the Member States through the EU Presidency.

The Parliament serves also as a forum for civil society and support groups to have a voice. I have worked with organisations such as Brainwave in Ireland. Such organisations can have strong interests in initiatives such as cross-border healthcare and the Parliament can give them an influence upon that process.

I will examine the role of the EU's research funding mechanism FP7 (and its successor FP8) and how this can play a role in combating epilepsy and mitigating its affects on sufferers. For example, recently published research partly funded by the EU has uncovered new information on the nature and causes of focal epilepsy.

**Influencing policy** – *Tarun Dua, Switzerland*

Epilepsy affects 50 million people worldwide, 80% of whom live in low and middle income countries. People with epilepsy are vulnerable because of the disorder itself and because of the stigma attached to it. Stigmatisation can lead to discrimination, and both the epilepsy itself and the stigma attached can lead to limitations in economic, civil, political, social and cultural rights. With effective and inexpensive treatments, more than two-thirds of people with epilepsy can be seizure free; however more than 75% of them in low and middle income countries are not appropriately treated.

In order to improve acceptability, treatment, services and prevention of epilepsy worldwide, Global Campaign Against Epilepsy (GCAE) was launched in 1997 as partnership of WHO, ILAE and IBE. One of the objectives of the GCAE is to assist departments of health in countries to identify needs and promote education, training, treatment, services, research and prevention of epilepsy in their countries.

This presentation will discuss the role of different stakeholders and synergies resulting from partnerships in influencing policies at local and national level. The various ways in which WHO provides technical support to policy makers and service planners will be presented. This presentation will also discuss the role of research, advocacy and other mechanisms to influence policy and decision-making.



## CONFERENCE PROGRAMME - FRIDAY 27<sup>TH</sup> AUGUST

**11.45 - 13.15**

EUCARE – Political Action Group session  
**More concerted action for more change!**  
 Chairs: Reetta Kalviainen, Finland & Janet Mifsud, Malta  
 (Interactive Session)

Apollo Room

Opening + Brief overview of PAG activities – *Hanneke de Boer, Netherlands*

ILAE/IBE Collaboration in Europe – the way forward – *Michel Baulac, France*

European Epilepsy Day: a short introduction – *Mike Glynn, Ireland*

Quiz

### More concerted action for more change!

We are all aware that living with epilepsy may not be easy. Apart from the seizures, people with epilepsy are known to have to deal with prejudice, misunderstandings and even discrimination! The EUCARE Political Action Group (PAG) was formed in January 2005, with the objective of focussing on social and political issues. The membership of PAG consists of representation from both IBE and ILAE, thus working toward concerted actions, which, as we all know by experience, stand the best chance to success!

We are firm believers in concerted action on all levels on large and smaller scales, which is why we selected as the title for last time's session: Concerted action for change. And we will continue to seek concerted action, also here, also today.

The purpose of the Resolution is to raise awareness about epilepsy among MEPs. Promoting the Resolution, however, should be a two-pronged effort – approaching the MEPs in Brussels by the PAG and through the national epilepsy associations who could approach their MEPs locally to seek their support – concerted action!

PAG is in the process of developing a European Epilepsy Day, however, this should be OUR day, thus we need YOUR input in shaping this - concerted action!

European Parliamentarians with an interest in epilepsy are being identified in order to try and raise awareness in the European Parliament - concerted action!

With the assistance of the European IBE and ILAE members/chapters we are hoping to undertake a survey to identify the level of epilepsy training provided during the full medical training period - concerted action! With the help of the European IBE and ILAE members/chapters we would like to compile a list of European Epilepsy Centres with the aim to create a list of centres which could be used by people with epilepsy when travelling or by doctors who were treating people with epilepsy in countries where specialist treatment was limited or not available - concerted action!

PAG calls on all of you for more concerted actions for more change changes!

**13.15 - 14.00**

**Lunch**

Hall outside Apollo Room



## CONFERENCE PROGRAMME - FRIDAY 27<sup>TH</sup> AUGUST

14.00 - 15.00

### Poster Presentations

Coordinator: Janet Mifsud, Malta

Hall outside Apollo Room

Posters will be displayed in the Hall outside the main session room. During this hour, delegates will also have the opportunity to present their posters.

14.00 - 15.00

Workshop EPI

### A comunicação social e a epilepsia

Chair: Dr. Rosalvo Almeida

Ariane Room

#### **A comunicação social e a epilepsia** - *Ricardo Rego & Nelson Ruão, Portugal*

Esta sessão faz parte integrante da 12<sup>a</sup> Conferência Europeia sobre Epilepsia e Sociedade e tem como objectivo reunir profissionais dos diversos veículos de comunicação social.

- objectivo principal é estimular a imprensa regional e nacional a diversificar as fontes e enfoques sobre a questão da epilepsia em Portugal.
- workshop pretende abordar os conceitos clínicos fundamentais da epilepsia, assim como as várias questões psicossociais que podem afectar esta população. Igualmente serão apresentados alguns dados sobre progressos recentes de âmbito científico e tecnológico.

Além de profissionais de saúde, temos a participação do Presidente da EPI, bem como depoimentos de pessoas com experiências de vida importante. Estes testemunhos incidirão sobre relatos de situações da vida com uma boa adaptação e convivência com a doença, na perspectiva do próprio paciente ou de familiares.

15.00 - 16.00

### Discussion Group

Chair: Victoria Dimech, Malta

Apollo Room

#### **Training for Success** – *Honor Broderick, Ireland*

Brainwave, the Irish Epilepsy Association was concerned that a disproportionate number of people with epilepsy were unemployed or underemployed compared to people without the condition. The association felt that this is not always due to a lack of vocational skills alone but can also be due to psychosocial aspects such as low self esteem or a lack of self confidence.

Brainwave had been involved in the provision of vocational pre-employment training for several years. In 1998 it took the decision to set up a programme specifically designed to ameliorate the negative impact of epilepsy on education and employment. Training for Success was developed in partnership with the Institute of Technology Sligo. This was the first time in Ireland that a voluntary organization and a third level institution worked collaboratively to develop a course for a specific client group. In developing Training for Success, Brainwave has adopted a holistic approach. This programme aims to contribute to the aesthetic, creative, emotional, intellectual and physical development of its students. One hundred and fifty two people have participated to date. These students have come from both Ireland and abroad. The programme is funded through FÁS, the Irish vocational training authority.

The presentation outlines: The historical development of the programme; participant profile; aims and objectives; description of the course; typical progression for participants; questions and answers.



## CONFERENCE PROGRAMME - FRIDAY 27<sup>TH</sup> AUGUST

### Working with politicians – Peter Scott, UK

This session will examine how to 'lobby' politicians, and why it is important to move epilepsy up the health agenda.

We will focus on:

- Why is it important to influence politicians?
- What messages connect with politicians?
- What can politicians do to help the epilepsy community?

We will also discuss the best methods of communicating with politicians to build a relationship, and how to work effectively with politicians to achieve our aims.

### Are smoking, caffeine, alcohol and stress risk factors for seizures? – Judit Bekes, Hungary

Introductory lecture for discussion group – suggested points to be discussed:

- Life-style choices – who or what controls PWE's life?
- Tension reduction techniques of everyday life and their effects: caffeine, alcohol seems to be one group, smoking another – some findings of the latest studies
- Stress – direct effects:
  - Can trigger seizure through an increase in the breathing rate (hyperventilation)
  - Long-standing or frequent experience of stress may cause hormonal changes which may influence seizure activity
  - Indirect effects: change of sleep patterns, disruptions in the medication taking regimen
  - Fear cycle: fear of seizures – stress – seizure – increased fear of seizures
- Stress-management options:
  - Coping – gaining back control – learned helplessness-learned optimism
- Stress management techniques:
  - Identifying personal sensitivities, vulnerabilities
  - Broadening one step further one's safety zone
  - Relaxation techniques, yoga, physical activities
  - Counselling, individual psychotherapy

16.00 - 17.00

Youth Session

**Drugs, sex and life style choices**

Apollo Room

### Drugs, sex and life style choices - Stine Strømsø, Norway

Epilepsy is one of the most unpredictable diagnoses you can get. Especially young people who are diagnosed in their teens struggle immensely with issues regarding alcohol, love, friends and future possibilities.

I was diagnosed with epilepsy at age 17. The diagnosis and the challenges this led to have given me positive and negative experiences throughout my adult life. Now being an adult who works with young people and adults with epilepsy has given me unique experiences that I will share with the audience.

Together with Nanette Mia Bohn who currently works as a consultant for the Norwegian Epilepsy Association's Youth Group we'll present some of the issues that young people with epilepsy deal with on an everyday basis as well as trying to conclude on how youngsters and their parents can deal with these issues.

Welcome to an inspiring, personal and informal session.

17.00 - 17.15

**Concluding Session**

*Athanasios Covanis, Greece & José Lopes Lima, Portugal*

Apollo Room

The conference will come to a close with the concluding session, summarizing and highlighting the information conveyed throughout the conference.



**IBE/ILAE Congress Secretariat**  
7 Priory Hall,  
Stillorgan,  
Dublin 18,  
Ireland