

## 26th IEC PROCEEDINGS

26<sup>th</sup> International Epilepsy Congress  
Paris, France, August 28<sup>th</sup> – September 1st 2005

**Sunday 28<sup>th</sup> August 2005**

**11:00 – 12:30**

**Salle 242AB**

**EUCARE Symposium**

**Influencing Policy - Achievements and Aspirations**

**Setting Up New Initiatives**

G. Stanculescu<sup>1</sup>

1) National Association Of People With Epilepsy In Romania, Romania.

In Romania, just as in many other countries, epilepsy is not an important issue for the authorities or for the general public. Thus, it is our job to make epilepsy an important issue if we want to improve in any way the epilepsy services. The way in which we can make epilepsy become an important issue is by setting up new and interesting initiatives in order to get the attention of those who can make a change. In different cultures/countries, there are different problems and different solutions to those problems. This is why there is no single right way to do things. And there are no guarantees that an initiative will be successful. However, it has always been our belief that if we do nothing we will get nothing. We have to be involved and to come up with new and interesting ideas all the time. For that we can look at the experience of other organizations and in order to make the ideas to work we can use tools such as the Epilepsy Action Pack. A tool for change. Following our participation at the 9th Epilepsy and Society Conference that took place in Malta in 2004, we had the inspiration to set up a new initiative as well as the instrument that helped us to make the idea work - the Action Pack. The project that we initiated was named 'Epilepsy beyond the dark' and it aimed at bringing a change in the situation of people with epilepsy. In what follows I will present our project, its objectives and its rationale, as well as the ways in which we tried to make it work and the ways in which the Action pack was useful to us.

**Obtaining Support from Third Parties**

J. Mifsud<sup>1</sup>

1) Caritas Malta Epilepsy Association, Malta.

Collaborations and partnerships with third parties, based on trust and shared decision making are fundamental to many NGOs existence. Such successful partnerships with third parties will increase the power and capacity of NGOs without compromising their own areas of responsibility. This is particularly relevant for NGOs involved in epilepsy issues as stake holders may be extremely varied e.g. government (local and national level), authorities, professional associations, pharmaceutical and other sponsors, with a varying interest and knowledge of epilepsy and its problems. Third parties prefer to deal with umbrella groups with clear objectives. It is essential to focus and first identify the problem to be solved or the situation to be changed with the third party. One may learn a lot by studying other successful campaigns. It is important not to just ask for support but explain how the project will be of mutual benefit. Useful tactics and tools and media to use, pitfalls to avoid and the importance of presenting a case with concise but accurate data will be discussed. Such partnerships may also be of great indirect benefit to the chapter members as it will provide empowerment incentives.

**Raising Awareness of Mortality and Other Sensitive Issues**

J. Hanna<sup>1</sup>

1) Director Epilepsy Bereaved

This session presents the case that raising sensitive issues such as epilepsy mortality is vital in ensuring epilepsy achieves priority with governments and health policy-makers; in ensuring that the issue of avoidable deaths is addressed by policy makers and by clinicians as well as providing a vehicle for positive action following individual tragedy. The session uses the experience in the UK where the historic neglect of informing, discussing or addressing epilepsy mortality during most of the 20th century has been turned round. Clinical guidelines now include discussion of SUDEP and governments across the UK have identified reduction of epilepsy mortality as an important part of the case for developing new national initiatives on epilepsy. The session uses two case examples - the first looking at the power of a campaign based on an individual case and the second looking at the campaign for the national investigation of epilepsy deaths that took place in England, Wales, Scotland and Northern Ireland during 2000 and reported in the National Audit of Epilepsy Deaths 2002. The case examples illustrate the lessons that can be learnt concerning what makes a successful campaign. These include the power of the individual experience in raising awareness of such a sensitive issue and the importance of a unique support network for individuals involved in such a campaign. This is shown particularly in relation to the Findlay case where a family in Scotland, supported by Epilepsy Bereaved, were involved in a four year Fatal Accident Inquiry into the sudden death of a young woman at 16, following some 10 years after the death of her mother from epilepsy aged 39. The power of this individual experience led to a judicial ruling that national epilepsy guidelines should be implemented and that SUDEP should normally be discussed with patients as part of the information available. The campaign for the National Audit into Epilepsy Deaths also relied heavily on the power of individual stories from bereaved families but also showed the vital need for a strong partnership between those most affected sudden death in epilepsy and individual clinician campaigners as well as the importance of a partnership between patient and clinical organizations and the need for support from the pharmaceutical industry. The result of the Audit was that all governments across the UK placed epilepsy higher on their agenda than ever before with a large number of national initiatives that at the very least have raised the profile of epilepsy and awareness of SUDEP. Looking more closely at the development of a campaign addressing mortality the message of the campaign is analysed looking at the importance of reaching a range of audiences including governments, policy makers, clinicians, patients, the media and the general public. The sensitivity of addressing death in epilepsy raises the importance of adapting the message to different audiences. The need to avoid messages that might increase anxiety to people living with epilepsy is addressed looking at ways in which communication can individualise fatality risks in the same way as already happens with other long-term conditions.

**Addressing Private Sector**

Y. Noormamode<sup>1</sup>

1) Edycs Epilepsy Group, Mauritius.

At the onset of the new century, partnership is high on the agenda of Edycs Epilepsy Group. No single sector whether Public, Private or Ngos can solve problems associated with epilepsy alone. It is therefore an undisputable fact that ALL the three Sectors that make

and evaluation, with the exception of one study (health records). Four studies were performed in rural and three in urban settings. Information was available only for Bolivia, Brazil, Ecuador, Chile, Guatemala, and Panamá.

*Conclusion:* Albeit substantially variable, the median prevalence of epilepsy in the elderly Latin-American population was similar to that in the northern hemisphere. Sources of variability in prevalence rates will be explored.

#### p903

##### Seizure Recurrence Following First-ever Seizure from Sleep in Adults

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1) Department of Neurology, Royal Perth Hospital, Perth, Australia

*Purpose:* A first-ever seizure arising from sleep has been reported to be associated with a higher risk of seizure recurrence in selected patient populations. This may have implications in identifying patients who should be treated after a first-ever seizure.

*Methods:* Prospective analysis of adult patients attending a hospital based first seizure clinic. Patients with prior seizures were excluded. The clinical characteristics of patients with a first-ever seizure from sleep were compared to those with a first-ever seizure during wakefulness. The occurrence of a second seizure was analysed in all patients with a minimum of one year follow-up.

*Results:* Seizures arose from sleep in 91 of 475 patients (19%). Focal epileptiform abnormalities were more frequent in the seizures-from-sleep group whereas generalised epileptiform abnormalities were more frequent in those with a first ever seizure during wakefulness. The demographic and clinical data including proportion treated were similar between the two groups. Seizure recurrence occurred in 43 patients (47%) with a first-ever seizure arising from sleep compared to 163 patients (42%) presenting with a seizure during wakefulness ( $p=0.41$ ). The time to second seizure and the proportion with seizure recurrence at one year were also similar. If the first seizure occurred during sleep the second seizure was highly likely to also arise from sleep (79% versus 13%,  $p<0.0001$ ).

*Conclusion:* A first-ever seizure from sleep was not associated with a higher risk of seizure recurrence and when present the second seizure was highly likely to also occur while asleep. These findings may have implications for treatment decisions and the counselling of patients with first-ever seizures.

#### p904

##### Epilepsy Prevalence in Bursa City Centre

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1) Uludag University Faculty of Medicine, Neurology Department, Bursa, Turkey 2) Uldag University Faculty of Medicine, Public Health Department, Bursa, Turkey

*Purpose:* This study is designed to find the epilepsy prevalence in the city centre of Bursa, a city situated in the west of Turkey. The study design was in accordance with the advice of the World Health Organisation (WHO) and study criteria were set up according to principles of ILAE Epidemiology and Prognosis Commission.

*Methods:* Out of 1,195,000 population, 2,124 people were asked to complete a standard questionnaire during a semi-structured face-to-face interview carried out by two neurology residents. Epilepsy patients filled another questionnaire after which they were examined by the same residents in order to classify the seizures.

*Results:* During the first interview, out of 190 suspected epilepsy cases, 26 (15 male, 11 female) were found to have epilepsy. Point prevalence of active epilepsy in this area was 8.4 per 1000. Life-long prevalence ratio was 12.2 per 1000. 61.50% of 26 patients had generalised, 11.50% partial, 11.50% both generalised and partial seizures and 7.60% had reflex epilepsy. Seizures started during the first decade of their lives in 50% of the patients. Only 34.60% were using antiepileptics regularly.

*Conclusion:* Since there are few prevalence studies in our country, multi-centred studies from different regions of the country should be

planned. Some new questions should be added to the standard questionnaire of WHO for epilepsy to make practitioners in our society diagnose epilepsy more accurately. This will help identify patients who should be diverted to tertiary care centres.

#### p905

##### Clinical and Aetiological Profile of New Onset Seizures in an Emergency Department in Northwest India

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1) Dayanand Medical College and Hospital (Old Campus), Ludhiana, 141001 India

*Purpose:* To determine the clinical and aetiological profile of new onset seizures presenting to the emergency department (ED) of a secondary-care, teaching, general hospital in North West India.

*Methods:* Patients over 12 years of age, with new onset seizure/seizure clusters in the 72 hours preceding presentation to the ED from 8 January 2003 to 30 June 2004 were evaluated using a tailored protocol with various biochemical, microbiological, neuroimaging and EEG investigations. The seizures were classified, according to the ILAE semiology, syndromic and aetiological classifications.

*Results:* New onset seizures comprised 110 (1.03%) of all admissions to the ED. Aetiological diagnosis was established in 83 (74.5%) cases. Aetiological diagnoses included: neurocysticercosis (12.7%), acute infarct (8.2%), uremia (7.2%), CNS infections (7.2%) and hyponatremia (5.4%). Computerised tomography (CT) (plain & contrast) was done on 88 patients and was found to be abnormal in 44 (50.0%). EEG was done on 20 (18.2%) of patients and was abnormal in 9 (45%) of these.

*Conclusion:* Neurocysticercosis, cerebral infarct, metabolic abnormalities and CNS infections were the most common causes of new onset seizures in the ED. CT scan has a high yield in the evaluation of new onset seizures presenting to the ED.

#### p906

##### Epidemiological Aspects of Adult Epilepsy in Libreville, Gabon

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*Purpose:* Epidemiological surveys indicate that the prevalence of epilepsy is higher in developing countries than in industrialised countries. The purpose of this study was to gain insight into the impact of epilepsy on adults in terms of frequency and risk factors in a Central African country.

*Methods:* A retrospective study was carried out in a department of neurology of Hospital Centre of Libreville, on patients hospitalised between 1 January 2000 and 31 December 2003. All patients with a diagnosis of epilepsy (ILAE criteria) confirmed by a neurologist and neuroradiological examination (EEG, CT scan or MRI) were included.

*Results:* 153 (12.5%) epilepsy patients were found among 1259 subjects admitted during the study period. 90 patients were males (sex-ratio= 1.4) and the mean age was 37.3 years. Generalised seizures were observed in 80.4% of cases and partial seizures in 19.6% of cases. 31 cases had idiopathic epilepsy, 27 had cryptogenic epilepsy and 95 had symptomatic epilepsy. The causes of epileptic seizures were: infection of the CNS (42.1%), stroke (30.5%), alcohol (15.8%), intracranial tumours (8.4%) and post-traumatic epilepsy (3.2%). Lastly 12 patients with a family history of epilepsy were identified. Treatment administered was: phenobarbital (55.5% of cases), valproic acid (38.6% of cases) and carbamazepine (5.9% of cases).