



INTERNATIONAL BUREAU FOR EPILEPSY

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FUNDEPI 2009



In Argentina there are around 200.000 patients with epilepsy. It is the most common illness of the chronic neurological pathologies and therefore the reason for more frequent consultations in the ambulatory services of neurology. On the other hand we should consider the social component that accompanies the epilepsy diagnostic, independently of the type and grade of epilepsy that it presents. The historical and cultural circumstances generate a particular situation that surrounds the patient, from the moment that that epilepsy is diagnosed. This requires a therapeutic accompaniment, for example self-help groups, providing information to the patient and family, as well as therapy with antiepileptic drugs or in some cases the surgical treatment. This is where FUNDEPI is present. It has the contribution of 15 specialized professionals, scholarship holders and patients dedicated to the work of self-help groups.

For 15 years it has a neurologist group, specialists in epilepsy who joined relatives and patients with epilepsy. They began to carry out different work tending to improve the quality of life of the fellows that suffer from epilepsy. The lack of diagnostic resources and treatment, the discrimination, the ignorance, and the stigmas surrounding people with epilepsy cause distress. Starting from March 7th 2001 when the National Law of Epilepsy was sanctioned, N° 25404, we have worked towards the sanction of the Regulation of the Law. Finally, the President of the Nation signed in January of the present year the Regulation of the National Law of Epilepsy (Decree 53/2009), sent by the Minister of Health of the Nation, in July 2008.



At the same time it is the beginning of a working process that guarantees through the compliment of the Law the best conditions of life for the patients with epilepsy.

For this reason on April 17th a meeting will be held in the national ministry of health of to work the best way to implement the Law and the adhesion on the part of the different jurisdictions to the Law and their Regulation. An invitation will be also sent to the scientific organizations and ONG's linked to the Epilepsy in order to constitute the Technical Commission.

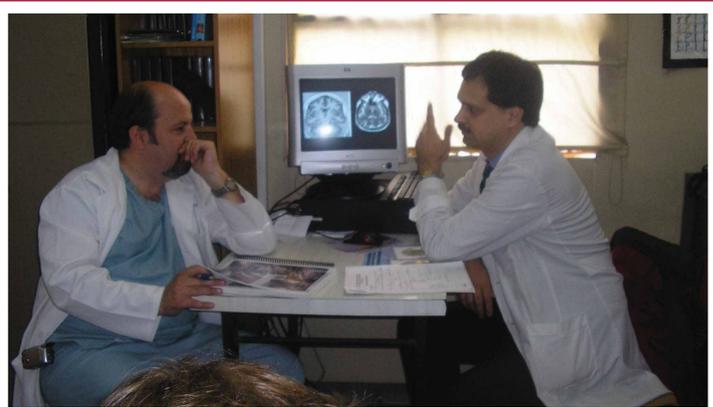
Furthermore, FUNDEPI is collaborating together with the Neurological Society Argentina and the epilepsy LEAGUE in the organization of the Epilepsy week that will be carried out from the 7 to September 2011. The same one consists on giving talks to patients, family and public in general, in different domestic places; The topics wil give information on causes, diagnostic and treatments of the epilepsy, as well as what to do before a seizure.

The Epilepsy week was born 10 years ago in the Hospital Ramos Mejias. Four years ago it was extended to all the hospitals of Federal Capital and in the year 2008 cities such as Santiago of the Tideland, the Silver, Ushuaia, etc have also joined the initiative. The important thing of this has been extended to public and private hospitals.

In the Hospital Ramos Mejia, the Epilepsy week was a success and was concluded with a toast.

CONTACT DETAILS

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B U D A P E S T

28th INTERNATIONAL EPILEPSY CONGRESS

 Eisai Supported by an educational grant from Eisai Co. Ltd





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JOINT EPILEPSY COUNCIL OF AUSTRALIA [JECA]



The Joint Epilepsy Council of Australia [JECA] was formed in 2003 and is Australia's full member of IBE. A national, not-for-profit coalition consisting of state and territory epilepsy organizations, JECA provides a framework for national and international representation to the benefit of all Australians living with epilepsy.

Member associations are community member-based epilepsy organizations providing services to local, regional and remote communities across Australia.

PRINCIPLE ACTIVITIES OF THE COUNCIL INCLUDE

- | all activities and responsibilities associated with IBE full membership
- | representation to the Australian Government on behalf of all people living with epilepsy
- | the provision of public position statements on major issues facing epilepsy
- | facilitating epilepsy conferences in Australia
- | liaising with overseas epilepsy organizations, and
- | providing an Australian forum for the interchange of ideas and improving practices and processes.



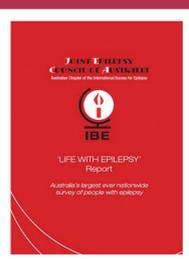
OUR VISION

By 2012, Australia will have:

- | an improved understanding of the impact epilepsy has on Australia, its people and its economy
- | an appropriate proportion of our world-class research effort targeted to the better diagnosis and treatment of epilepsy
- | communities that are increasingly aware of epilepsy, what it is, how to manage it, so that people with epilepsy can live without stigma and be active community participants
- | workplaces that are informed, free of stigma, and support those with epilepsy to remain in employment
- | health services that reflect world's best practice in promoting the right care by the right health professional
- | support provided to people with epilepsy and their carers so that they are assisted in their pursuit to manage their condition and actively participate in the community.

JECA INITIATIVES & ACHIEVEMENTS

- | First ever nationwide survey 2006
- | A National Strategy for Epilepsy in Australia: 2007-2008 Pre-Budget Submission
- | Life with Epilepsy Report 2007
- | Epilepsy debate in Parliament 2007
- | Parliamentary Friends of Epilepsy launch, Parliament House, Canberra 2008
- | JECA presents vision for epilepsy to Parliamentary Friends of Epilepsy 2008
- | Parliamentary Friends of Epilepsy "Inquiry into Epilepsy" announced 2008
- | JECA submits Terms of Reference for Inquiry to Parliamentary Friends of Epilepsy 2009



LIFE WITH EPILEPSY REPORT

In 2006 JECA member organizations conducted the first nationwide survey on the impact of living with epilepsy. *The Life With Epilepsy* report, published in 2007 provided a valuable insight into the impact of living with epilepsy – both people with epilepsy and those who live with them. This report informed and strengthened our discussions with Government, while identifying areas in need of further applied research.

PARLIAMENTARY FRIENDS OF EPILEPSY

The formation of the Parliamentary Friends of Epilepsy in 2008 is a major development to advancing the epilepsy cause as a policy area of significance within the Parliament.

At the first meeting, JECA outlined its 6-point vision and action plan for improved understanding of the economic and social impact of epilepsy. Committed to making lasting change for people living with epilepsy and their carers, the Friends proposed an Inquiry into Epilepsy be conducted giving all stakeholders the opportunity to inform politicians and policy makers of the impact of living with epilepsy. With the support of the Parliamentary Friends this inquiry will inform the Parliament on the unmet needs of all Australians living with epilepsy.

DISCUSSION PAPERS

JECA works closely with academics and consumer organizations to facilitate discussion papers on epilepsy that aims to inform politicians and health care policy makers of the impact of living with epilepsy.

INTERNATIONAL FORUMS

JECA's engagement at international forums informs our own work while contributing to the work of the international epilepsy movement. Representation includes:

- | Robert Cole: Chair, IBE Editors Network
- | Rosemary Panelli: NINDS Sudden Unexpected/Unexplained Death in Epilepsy (SUDEP) Workshop, Washington. 2008
- | Denise Chapman: Epilepsy Bereaved AGM, UK. 2008
- | Dr Christine Walker: 7th AOEC, Xiamen. 2008

CONTACT DETAILS

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