



# INTERNATIONAL BUREAU FOR EPILEPSY

11 Priory Hall, Stillorgan, Dublin 18, Ireland

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## CARITAS MALTA EPILEPSY ASSOCIATION

### ON THE SIDE OF PEOPLE IN NEED

#### INTRODUCTION

The Caritas (Malta) Epilepsy Association was set up in 1996, in order to help people who have the condition and their families. It is estimated that in the Maltese Islands there are over three thousand persons who have epilepsy. At the moment the association has about 235 members of whom 160 have the condition themselves.

#### AIMS

The mission of the association is to improve the quality of life for people with epilepsy.

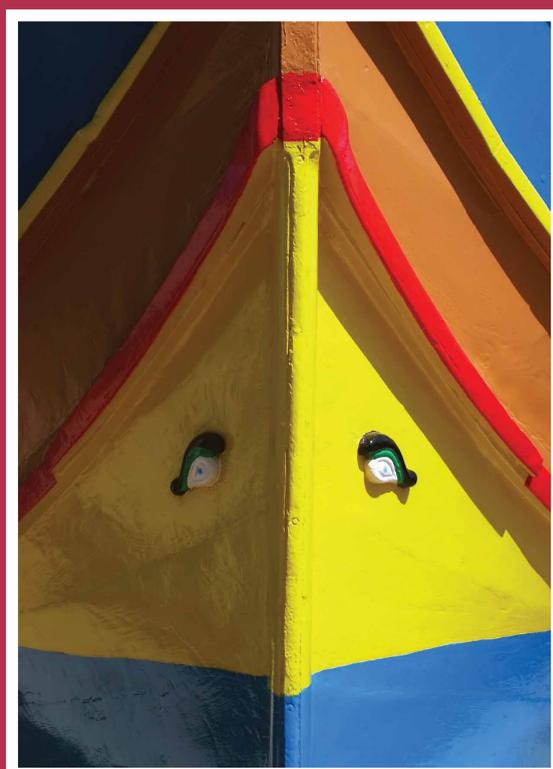
The association's aims and ideals are:

1. To promote public awareness and education about epilepsy and the needs of people who have the condition.
2. To improve the public image of the person with epilepsy.
3. To enhance the self-image, self-confidence and self-reliance of people with epilepsy.
4. To stifle local discrimination of people with epilepsy and minimise the social consequences brought about by epilepsy.
5. To counsel and educate persons with epilepsy and their families or their legal guardian/s on coming to terms with and adapting to the condition.
6. To present the interests, rights, needs, grievances and problems of persons with epilepsy to the notice of policy makers.
7. To promote the exchange of information with other organisations.
8. To co-ordinate with other persons wishing to form other organisations for the welfare of persons with epilepsy and/or Caritas (Malta) Epilepsy Association their families or their legal guardians.
9. To encourage and promote research.

#### ACTIVITIES

All these aims are achieved through the association's activities:

- | Talks and interviews on local radio, TV stations and daily papers.
- | Press releases on local newspapers.
- | Printing and distribution of leaflets on various aspects of epilepsy in schools, hospitals and clinics.
- | A one hour video film about epilepsy in Maltese, describing the various types of seizures, medication and local experiences. This video is being shown in schools and sold to various organisations.
- | Various meetings with the Health Authorities, Ministries of Health and Social Policy regarding improvements at Mater Dei Hospital with respect to equipment and service and also for the keeping of a register for statistical purposes in order to know better the number of persons with the condition.
- | Membership with IBE and local Federation of Organisations for Persons with a Disability.
- | Frequent committee meetings and monthly group meetings.
- | Fund raising activities.
- | Participation in EYIE activities and attendance at international conferences.
- | Setting up a youth branch within the organisation.
- | Choosing the 14th February as the National Epilepsy Day.
- | Printing and distribution of leaflets on various aspects of epilepsy in schools, hospitals and clinics.
- | National Epilepsy Conference inaugurated by His Excellency the president of Malta Prof Guido de Marco on the 3rd November 2001, with Mr Philip Lee and Ms Hilary Mounfield as special guest speakers.
- | National Epilepsy Conference inaugurated by His Excellency the president of Malta Profs Guido de Marco on the 2nd February 2003 with Mr John Bowis and Mr John Chaplin as special guest speakers.
- | Hosted IBE 9th European Conference on Epilepsy 'Focus on Change' at the March 2004
- | Co-ordinator of EU Grundtvig funded project: Curriculum development for PAMs in epilepsy
- | National Epilepsy Conference February 2008 with Prof Martin Brodie and Dr Greg Rogers as special speakers
- | Organization of inservice training courses for teachers and learning support assistants in conjunction with Ministry of Education.

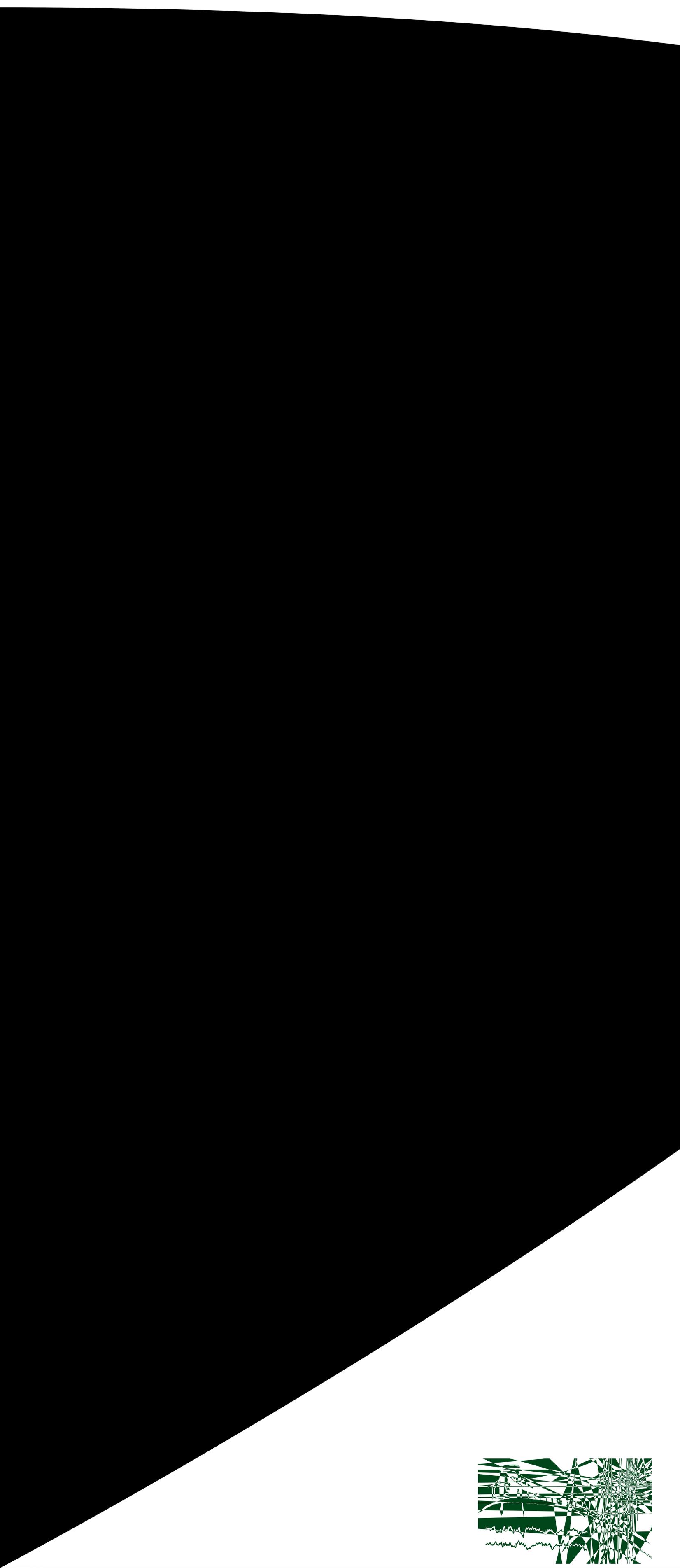


## B U D A P E S T

### 28th INTERNATIONAL EPILEPSY CONGRESS

 Eisai Supported by an educational grant from Eisai Co. Ltd







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## GROUP "ACCEPTATION" OF PERSONS WITH EPILEPSY

**Reunión Anual Nacional del Capítulo Mexicano de la Liga Internacional Contra la Epilepsia**  
30 de Septiembre al 03 de Octubre 2009

**\* Talleres**  
**\* Conferencias Magistrales**  
**\* Exposición Comercial**  
**\* Trabajos Libres**

**III CONGRESO NACIONAL DEL CAPÍTULO MEXICANO DEL BURÓ INTERNACIONAL PARA LA EPILEPSIA**  
2 al 4 de Octubre 2009

**30 de Septiembre al 03 de Octubre**

**SAN LUIS POTOSÍ**  
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**GADEP** Grupo "Aceptación" de Epilépticos  
Capítulo Mexicano del Buró Internacional para la Epilepsia

**EPILEPSIA**

**PROGRAMA 2009**

**AUDITORIO**  
Hospital 30 de Noviembre  
Félix Cuevas 540 Col. Del Valle, México, D.F.  
Primer sábado de cada mes  
9 A.M.

**Presidenta**  
Dra. Lilia Núñez Orozco

**Secretario**  
Dr. Noel Plascencia Alvarez  
Servicio de Neurología del CMN 30 de Noviembre

**PROGRAMA 2009**  
Primer Sábado de cada mes

**Enero 3**  
Epilepsia - Conceptos generales  
Dra. Lilia Núñez Orozco

**Febrero 7**  
El diagnóstico de las crisis epilépticas  
Dra. Nancy Bertado Ramírez

**Marzo 7**  
Cuando parece epilepsia y no lo es  
Dra. Laura Ordóñez Boschetti

**Abril 4**  
El tratamiento multidisciplinario de la epilepsia  
Dra. Lilia Núñez Orozco

**Mayo 2**  
El tratamiento quirúrgico de la epilepsia de difícil control  
Dr. Noel Plascencia Alvarez

**Junio 6**  
La epilepsia, las leyes y los derechos humanos  
Lic. Angel Zarazúa Martínez

**Julio 4**  
Aprendizaje y deterioro mental en epilepsia  
Dr. Miguel Ángel Villa Rodríguez

**Agosto 1**  
Epilepsia y calidad de vida  
Dra. Sandra Quiñones Aguilar

This self-help group was founded in 1991 and affiliated to the IBE on 1993. This was the first association in Mexico dedicated to the psychosocial problems of Epilepsy, it has grown up and has been known in the whole country, encouraging other people to found groups with the same goal in other cities, like Monterrey, Guadalajara, Zacatecas, Aguascalientes, etc.

The younger groups are mainly directed by people with epilepsy, but others are coordinated by neurologists. All groups work around the importance of giving good information about epilepsy and advise patients about how to cope with the disease, about the new treatments and how to use them, always trying to give the right place to their treating doctors.

Since these type of groups have as the main objective to improve self-esteem, all need of Psychological support, but other needs as education and places to work are other secondary objectives to reach.

In the last years, our group has been trying to search an approach to other Mexican associations to improve the team work, so we have realized two bi-annual congresses in different cities where other groups exist and where the Mexican Chapter of ILAE congresses have been held. The III Congress is scheduled for October of this year.

**Septiembre 5**  
Epilepsia y familia  
Mesa Redonda. Coordinada Dra. Lilia Joya

**Octubre 3**  
Problemas psiquiátricos en la epilepsia  
Dr. Hugo Martínez Lemus

**Noviembre 7**  
El trabajo y la epilepsia  
Lic. Oscar Fernández, Dr. Jorge Verges Duval

**Diciembre 12** (segundo sábado)  
CONVIVIO DE FIN DE AÑO

**HORARIO**  
9:00 Registro y refrigerio  
9:30 Introducción  
10:00 Tema programado  
11:00 Preguntas y respuestas  
12:30 Sesión de apoyo neuropsicológico

**Actividades:**  
• Sesiones informativas mensuales  
• Información por internet [www.epilepsiahoy.com](http://www.epilepsiahoy.com)  
• Apoyo neuropsicológico Dra. Aura Moreno Bernal  
• Asesoría legal Lic. Angel Zarazúa Martínez  
• Bolsa de Trabajo Lic. Oscar Fernández  
• Banco de Medicamentos Isabel Plascencia  
• Apoyo psicológico Psic. Francisco Javier Alonso GADep Amistad

**Talleres los demás sábados de cada mes 9 a 13 hrs.**  
• Bufalo 27, Col. Del Valle  
• Grupo de Teatro  
• Actividades recreativas y más

*Le hallé significado a mi vida ayudando a los demás a que le dieran a sus vidas un significado.*

V. Frankl

El Grupo "Aceptación de Epilépticos", fundado en 1991, es un grupo abierto a todas las personas con epilepsia y sus familiares para proporcionar información, asesoría, apoyo y elevar el autoestima de las personas con epilepsia. Desde 1993 constituye el Capítulo Mexicano del Buró Internacional para la Epilepsia, organismo internacional que agrupa asociaciones de todos los países para apoyar a las personas que padecen epilepsia.

**Informes:**  
5200-3474, 5200-3452  
[www.epilepsiahoy.com](http://www.epilepsiahoy.com)

**Buró Internacional para la Epilepsia**

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## MONGOLIAN EPILEPSY ASSOCIATION



Dear outstanding person,

By using this precious occasion meeting you in Budapest, let me express my warmest greetings to all of you on behalf of Mongolian Epilepsy Association, their members, hundreds of person with epilepsy as well as their families.

Mongolia is the country with the vast territories (1.5 million square kilometers) and small and widely spread population (about 2.6 million), which has adopted in 1990 the democratic governance.

During this process of transition to market oriented economy from the centrally planned one, our country's economy is facing hardships as well as the health organization and hospitals.

Despite these hardships, we – doctors still sincerely continue to do our best for the health of our people, overcoming all financial and other constraints. There are so many pending issues in our country in regard to health, care and treatment of patients with epilepsy as well as their social issues.

International organizations engaged in epilepsy such as ILAE and IBE, their management and all employees have granted to our organization and our country their selfless and heart full support in developing in recent years the epilepsy care of Mongolia.

In 2007 and 2008 MEA have successfully implemented "Quality of Life Program" – Improving public knowledge for epilepsy in Mongolia which supported by the Promising Strategies Program of the International Bureau for Epilepsy.

This is why, we'd like to express our utmost gratitude and thanks for this support and express our belief that this support and cooperation shall be prospering in the future.

Our sincere wishes for the successful completion of this important event solving many important issues.

Let me extend all the best wishes and health to all doctors, experts, employees, supporting people and organizations as well as sponsors for their support and assistance.

God bless all people with epilepsy.

Thank you



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## THE MOROCCAN SOCIETY AGAINST EPILEPSY (MSAE) SIDE BY SIDE WITH EPILEPTIC PATIENTS IN MOROCCO



### AUTHORS

Harkani Abdellatif<sup>1</sup> and Kissani Najib<sup>2</sup>

Epilepsy still constitutes a serious health problem in Morocco its prevalence is estimated at 1.1% (1), the great majority of our epileptic patients have a very poor knowledge about epilepsy and most of them resort to unorthodox methods especially in rural areas, on the other hand our patients suffer from professional and social discriminations.

The MSAE, an non-lucrative association, was created to promote and improve the management of epilepsy, to sensitise patients, their families and all persons concerned by epilepsy to eradicate the distort beliefs about epilepsy, to collaborate with regional and other national societies involved in epilepsy and of course to support patients and their families to overcome all kind of material, social and professional difficulties.



### TRYING TO COVER NOT ONLY SOUTHERN MOROCCO

Since its creation in November 2001, our society was regional (regional league against epilepsy in Marrakech and its countryside), and since 2005, it becomes a national society having in charge the coverage of the national territory, because of the inexistence of any society implicated in social aspects of epilepsy (illustration 1).

Illustration 1: Progression of coverage of national territory since 2001.

Illustration 2: Organizing committee of the last scientific journey.

Illustration 3: The MSAE implicates successfully young doctors, medical students and nurses in the organization of social journeys.

Illustration 4: Active participation to the last social and scientific journey, June the 9th 2007.

Illustration 5: Scientific meeting for general practitioners.

### THE PERSPECTIVES OF MSAE

**IN SHORT TERM**, MSAE will consolidate its main priorities: on one hand, educate and inform general public and sensitize epileptic patients and their families; and on the other, improving the management of epilepsy in Morocco, especially in cities without neurologist with the partnership of general practitioners.

Since December 2006, patient's cards and brochures were distributed to all adherents; and during 2008, posters in Arabic, informing about epilepsy, highlighting bad aspects of traditional practices and showing good and bad attitudes.

We will start video projections in public transport and spot TV programs about epilepsy, to assure more sensitization concerning epilepsy.



**IN MEAN AND LONG TERM, WE EXPECT** MSAP will cover more than 70 of Moroccan territory, and will create delegations in other big cities; a bimonthly bulletin will be set-up to keep adherents and practitioners updated.

We expect to update the driving licence legislation for epileptic patients. MSAP will better collaborate with the Moroccan League against Epilepsy, to decentralize epilepsy surgery in Morocco as it remains concentrated only in Rabat city.

In the end, we hope to establish good relationship between other neighbouring countries, North African, francophone, and especially sub-Saharan countries, to share and also to diffuse our experiences.

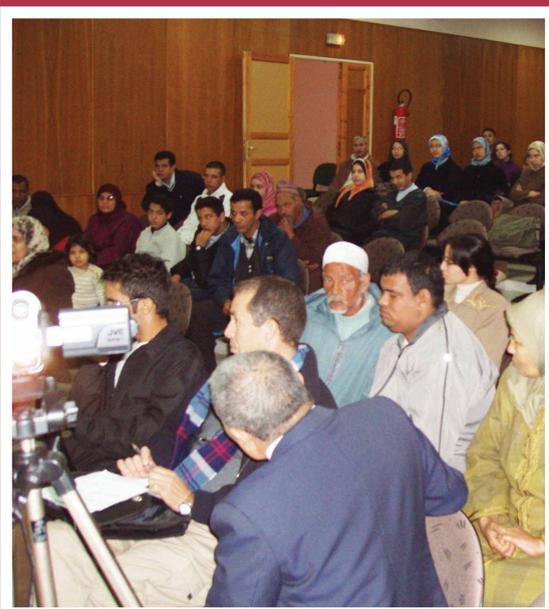
### MSAE HAS CHOSEN TWO STRATEGIES

**A-COVERING FAR CITIES WITHOUT NEUROLOGIST BY SPECIALIZED REGULAR CONSULTATIONS:** Morocco, as the other North African countries, suffers from the inequitable repartition of neurologists on the national territory; this situation makes difficult the access to specialized consultations for people living in small cities and rural areas, especially in southern Morocco (less than 10% of neurologists for 30% of Moroccan citizens).

We started since April 2006 by insuring four monthly specialized consultations in cities without neurologists. In the end this initiative will prevent people from expensive displacement to Marrakech. This approach will attenuate on the other hand medical demand in the neurology department of Marrakech and could assure a better management of neurological diseases in general and particularly epilepsy in cities without neurologists.

**B-WORKING SIDE BY SIDE WITH GENERAL PRACTITIONERS:** because of the big number of epileptic patients in Morocco, the small number of specialists and the feeble implication of general practitioners in epilepsy management, we realize that the best way to improve management of epilepsy is to focus on general practitioners, and we established different collaborations with local health authorities and pharmaceutical laboratories to cover these regional sessions for training and sensitizing general practitioners; In 2008 a regular program will be instituted for these meetings. (Illustration 5).

In the end, we hope to generalize our social activities to other cities in Morocco, through delegations, and to establish collaboration between our society and other societies, especially in African countries.



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