Global Activities

Caroline Morton, Co-ordinator GCAE Newsletter
ILAE/IBE/WHO Global Campaign against Epilepsy

Dear Readers,

This issue contains information on initiatives/activities, which have been organised in two different regions of the world: Europe and Africa. As you will read, our colleagues and friends in those two regions are very active and keen to organise activities under the Global Campaign against Epilepsy, which we gratefully acknowledge.

We also welcome all readers to submit articles on Global Campaign initiatives in which they’ve been involved. We will be happy to publish articles in future issues of the newsletter. We are also very keen to include photographs.

Furthermore, we would also urge you to forward this newsletter to your colleagues and friends, in order that we may increase our readership, and thus, inform more people about the Global Campaign against Epilepsy.

The more people who are aware of our activities, the more we can achieve in the long run.

We also include a special message from Prof. G. Avanzini, President ILAE, concerning the terrorist attacks in America on Tuesday, 11 September. These events have deeply affected people from all nations, cultures and religions.

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<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Attack on America</td>
</tr>
<tr>
<td>2</td>
<td>World Health Day Activity in Georgia</td>
</tr>
<tr>
<td>3</td>
<td>Lithuanian Chapter ILAE</td>
</tr>
<tr>
<td>4</td>
<td>Togo Association Against Epilepsy</td>
</tr>
<tr>
<td>5</td>
<td>Tunisian Association against Epilepsy</td>
</tr>
<tr>
<td>6</td>
<td>Future Congresses</td>
</tr>
</tbody>
</table>

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Attack on America

We are deeply affected by the immense tragedy, which has taken place in New York and Washington on Tuesday, 11 September. A date, which will never be forgotten.

Prof. Giuliano Avanzini, as the President of the International League against Epilepsy, sent the following message to the American League chapter to share his first emotions with them soon after he heard about this tragedy:

_On behalf of the International League against Epilepsy, I want to tell the friends of the American Epilepsy Society that we are all close to them in this tragic time. As members of the ILAE, we are looking forward to seeing a world in which no person’s life is limited by epilepsy._

_As members of mankind, our dream is to contribute in building a world where human relationships are based on mutual respect and solidarity, a world where there is no place for violence, the most depraved and stupid perversion of the soul_”

These thoughts are echoed by the Secretariat and everyone involved in the Campaign. We would like to extend the above message to our friends at the Epilepsy Foundation, and all others throughout the USA, whose lives were affected by these dreadful events.
World Health Day activity in Georgia
Stop exclusion – dare to care!

N. Okujava
This event was the official launch of the Global Campaign against Epilepsy in Georgia. A briefing, dedicated to World Health Day, was held at the Ministry of Health and Social Affairs. Participants included the Minister, First Deputy Minister, Head of Mental Health Care in Georgia and representatives from the IBE Chapter.

Activities devoted to the World Health Day were announced and a press release was distributed.

Lithuanian Chapter of ILAE
Activities carried out under the Global Campaign against Epilepsy

M. Endziniene
The Lithuanian Chapter of the ILAE has carried out many activities under the Global Campaign against Epilepsy and would like to share these with the readers:

April 2000: first meeting on comprehensive care for people with epilepsy and their families with the participation of neurologists, social workers, psychologists, nurses, etc. This was the first time a multidisciplinary team discussed these issues.

September 2000: meeting of the Lithuanian Society of People with Epilepsy, discussing issues on living with epilepsy, again with a multidisciplinary team, including a lawyer.

December 2000: another meeting on comprehensive care, with more than 200 participants. All of the above meetings have been covered in the Lithuanian press under the heading Global Campaign against Epilepsy.

A World Health Day activity was also organised; a special bulletin was distributed not only for their members, but also for different specialists outside the Chapter, to the Lithuanian WHO office, Ministry of Health and the mass media. On 7 April a discussion on epilepsy took place on central television, radio and in the press.

Also, from April until mid-June an art competition for children with epilepsy was organised. The drawings were exhibited in the streets of Kaunas, at the entrance of the venue for the 6th International Baltic Child Neurology Conference (250 participants) which took place from 13-16 June, in which again, the Global Campaign against Epilepsy was highlighted.
Togo Association Against Epilepsy (TAAE)

K. Grunitzky

The Association organised a general assembly in April 1999 and was officially installed (made a Constitution and by-laws) on August 25, 1999. Members of the Association are health professionals.

National consensus workshop on a plan to bring the person with epilepsy in Togo out of the shadows.

Other NGO’s, which have as their members people with epilepsy, parents with a child with epilepsy and lay persons have been set up in some regions of Togo. A federation of all these groups is in development.

TAAE initiated 3 pilot studies, supported by the WHO Regional Office in Africa, which can be considered as the beginning of the implementation of the GCAE in the country. Due to space restriction, in this article we will only report on two of them.

The first project was initiated by an NGO, “le Sefrah”, which was founded by the Church of the Assembly of God. This NGO is very present in the North of Togo. This region is situated in the Volta delta in an area with endemic diseases and in the belt of meningitis. For a population of around 200,000 inhabitants, the health district of Tone counts 3 medical professionals. The majority of the health personnel are spread out through the region from the central office.

• the level of use of the health services is less than 30%
• vaccinations are below 40%

The region is very under-served by the health plan. The activities of “Sefrah” originally aimed at the ophthalmological complications of onchocercose but more and more they also concern other handicaps. “Sefrah” sends agents, who participated in a rehabilitation programme in the community, to all the villages in the region. These agents approached the responsible people in “Sefrah” after strong demands from the community to take care of epilepsy.

A research project was developed by “Sefrah” and supported by the National Mental Health Programme (NMHP) of the Ministry of Health. The objectives of the project were:

• The integration of epilepsy in the activities of the agents
• Identification of people with epilepsy
• Treatment of identified people with epilepsy

• Monitor these new activities
• Evaluation of the results

The NMHP then asked the Association (TAAE) to support the project by:

• Offering a one week training to the agents (48 hours)
• Realising a KAP survey in the district
• Examining 248 people identified by the agents (clinical investigation and EEG)
• Realising an epidemiological survey. The prevalence of active epilepsy was 17.3 pro mille (CI: 95% 14.6 – 20) Adjusted for sex it was 19.4 pro mille (CI: 95% 15.3 – 23.5) for men and 15.4 pro mille (CI 95% 11.9 – 18.9) for women
• To provide the agents with phenobarbitone for the follow up of the treatment prescribed by the members of the NMHP and TAAE
• Evaluation

A team of health professionals of TAAE (neurologists, paediatricians, experts in parasitology, etc.) trained the agents during a week. A survey on epilepsy was conducted at the end of the training.

The agents supervised by their trainers traced 248 people with epilepsy among 194,000 inhabitants with the help of a questionnaire consisting of 5 questions. The team of TAAE examined these people with epilepsy and their diagnosis was confirmed.

The specific outcome of this study was the apparent absence of adults among the people with epilepsy who were identified. (18/248)

• The agents found especially febrile convulsions
• Seizures as a consequence of a disease of the brain (meningitis, measles)
• The few adults with epilepsy who were found were those, whose seizures were known to everybody (the seizures happened in public places) and who were rejected by the community.

The conclusions of this work:

• the personnel of the NGO remained more motivated that the health personnel
• the person with epilepsy still remains in the shadows because the level of utilisation of the health services in the district is 30%, vaccination is below 40% and less than 30% get medical guidance at child birth
• the participation of the community is limited because of social and cultural considerations
• the number of people with epilepsy in the district is estimated between 1,000 and 2,000
• the provision of care to people with epilepsy by non-governmental organisations has proven to be very effective. The project will be continued by this NGO whom we offered our technical support

The second project took place in the Sotouboua district. This district is situated in the central Region. It receives financial and technical support from La GTZ, a German co-operation.
In 1987, 141 people with seizures were seen at the centres for the first time. None of these patients was offered treatment.

The objectives of the project were:
- To take charge of the known people with epilepsy in the district of Sotoboua
- To set up an IEC (special epilepsy clinic) about the disease and the treatment close to the family
- Support social reintegration of people whose epilepsy is well controlled

The following are the phases for the realisation of the project:
- the medical staff will be trained by TAAE
- the most important antiepileptic drugs (aed’s) are provided to the medical leader of the district
- in every centre each staff member sees 2 to 3 people with epilepsy who live in a situation where they are rejected by their community (35 in total). This is free of charge.
- In the course of 12 months 180 people with epilepsy were seen regularly. The seizures were controlled in 60% of the cases and less frequent in 13%.

The utilisation of the health services during the second year had increased from 38 – 50%. Unfortunately at the end of the second year we had a disruption in the national stock of aed’s. The demand dried up and the people with epilepsy disappeared in the shadows, the lack of light plunged them into obscurity again.

**Tunisian Association Against Epilepsy**

**Activities under the Global Campaign against Epilepsy**

**A. Mrabet**

The following activities were carried out:
- a leaflet on epilepsy and work was printed and distributed to employers dealing with people with epilepsy.
- A workshop was held to enhance awareness and change attitudes of colleagues and employers of people with epilepsy
- An evaluation of the failure of school and children with epilepsy was evaluated over a 3-year period (1995-1997) and this was presented in the 1st meeting of the National Centre of School and University Medicine
- A study on the knowledge and attitudes of teachers towards epilepsy was started in 1999 and the results were presented as a poster at the 24th International Epilepsy Congress which took place in May in Buenos Aires, Argentina
- The 1st National Day on Epilepsy was organised on 22 April and was a large success. People with epilepsy participated, together with their families and professionals in the field of epilepsy. During this day people with epilepsy could ask questions on treatment and social aspects, plus there was also an opportunity to surf the web site of the Tunisian Association against Epilepsy, and to learn how to participate to keep this web site as a permanent contact between the people with epilepsy and the professionals caring for people with epilepsy.

**Activities of the Secretariat**

The activities of the Secretariat did not cease during the summer period. Contacts with China were maintained in order to publish an article on the results of the first phase of the Demonstration Project in a peer reviewed journal. In Senegal and Zimbabwe the protocols for the Demonstration Projects are being finalised according to plan, which means the Projects should be ready to begin in October. In Argentina a meeting on the preparations for a Demonstration Project took place and the protocol is being worked on, to be finalised at the beginning of next year.

A meeting took place on the implementation of the Campaign in the African Region, particularly in Zimbabwe. Similar meetings are being organised in South East Asia and the Western Pacific Regions, to take place later this year.

A survey on Country Resources in Epilepsy was prepared and is now being sent to representatives in many countries.

And last but not least a Newsletter was prepared of which this is already the third issue.

**Future Congresses**

Where Global Campaign sessions are planned:

- **7th Mediterranean Epilepsy Conference**
  22-25 November 2001, Athens, Greece

- **8th Epilepsy & Society Conference**
  17-19 May 2002, Lloret de Mar, Spain

- **2nd Latin American Congress on Epilepsy**
  29 May-1 June 2002, Foz do Iguassu, Brazil

- **4th Asian Oceanian Epilepsy Congress**
  12-14 September 2002, Nagano, Japan