

**INTERNATIONAL LEAGUE AGAINST EPILEPSY,
EAST MEDITERRANEAN REGION CHAPTER CONVENTION**

Friday, 8th March 2019, 18:00 – 19:15

Hotel les Jardins d'Agdal, Avenue Mohammed VI, Marrakech 40000, Morocco

List of Attendance

ILAE Management Committee

President, Samuel Wiebe CANADA
Treasurer, Helen Cross UK
Secretary General, Ed Bertram USA
Past President, Emilio Perucca

East Mediterranean Region Executive

Chair, Chahnez Charfi Triki TUNISIA
Past Chair, Hassan Hosny, EGYPT
Member, Ghaieb Al Jandeel, IRAQ
Member, Adel Misk, PALESTINE

Member, Reda Ouazzini Taibi, MOROCCO

Chapters

Listed on the roll call under agenda item (1)

Young Epilepsy Section (YES)

Ahmed El Kady, EGYPT
Reem Al Youbi, SAUDI ARABIA

Staff

Gus Egan, Chapter Services

Agenda

- (1) 18:00-18:20 The EMR: what was done and the challenges on the future, CC Triki
- (2) 18:20-18:40 ILAE at its 110th anniversary: Current initiatives and future perspectives, S Wiebe
- (3) 18:40-19:00 From the WHA Resolution to a Global Action Plan for Epilepsy, E Perucca
- (4) 19:00-19:15 Presentation of the activities of the chapter

1) The EMR: What was done and the challenges on the future, CC Triki

C Triki opened the meeting and welcomed all present. She took the Chapter roll call as follows:

Egypt	Nirmeen Adel Kishk
Egypt / YES Rep	Ahmed El Kady
Iraq	Ghaieb Al Jandeel
Jordan	Absent
Kuwait	Absent
Lebanon	Absent
Libya	Nagi Barakat
Morocco	Reda Ouazzani Taibi
Oman	Abdullah Al Asmi
Palestine	Adel Misk
Qatar	Absent
Saudi Arabia	Raidah Al Baradie

Saudi Arabia	Lamyaa Jad
Saudi Arabia / YES Rep	Reem Al Youbi
Saudi Arabia	Bandar Aljafen
Syria	Absent
Tunisia	Chahnez Charfi Triki
Tunisia	Mohamen Fredj
UAE	Absent

Applicant Chapters

Algeria	Mohamed Djellaoui
Bahrain	Adel Al Jishi
Sudan	Abdalla Abdelrahman
Yemen	Apologies

She highlighted the importance of communication amongst the Chapters in the region and asked everyone to be mindful of this moving forward. As Chair of ILAE-EMR, she had sent an email about courses/fellowships but got few replies. She asked everyone again to improve their communication in order to be more efficacious in the development of the region on the field of epilepsy.

Next, she introduced the members of the Management Committee and also welcomed the two members of the Young Epilepsy Section (YES) and congratulated Dr Reem Al Youbi who was elected as a chair of EMR-YES.

2) The ILAE at its 110th anniversary: Current initiatives and future perspectives, S Wiebe

S Wiebe stated this meeting would follow an informal dialogue to highlight each Chapter's needs. This will help the ILAE determine how to operate and what to support in the region. The ILAE is interested in achieving its mission through engaging people and education; he stated that a whole suite of education initiatives is being launched soon. His desire is to improve the Congresses and ensure that people get the best profit from them. He encouraged all to engage with CC Triki, Chair of the region, in this regard.

He reminded everyone that the ILAE was founded 110 years ago in Budapest and while some Chapters have been in existence since that time, some are new today, like those applying for membership in the region citing Bahrain as an example. He pointed out that every country/Chapter is at a different stage of development. He opened the floor to the Chapters to explain the issues in each country.

TUNISIA

M Fredj, Secretary General of the Tunisian Association Against Epilepsy, stated that in Tunisia some civil unrest has interrupted their ambitions in the past. However, even though he has not been as active in the recent past, he remains committed to working more with the Chapters in the region. He cited the Franco Maghrebian activities in Tunisia that the Chapter organized. He suggested the EMR look to other regions with established education initiatives for inspiration to establish its own.

OMAN

A Al Asmi, President of the Omani Chapter, introduced his as one of the newest Chapters in the region, at only one year old. They do not have enough epileptologists in their country, noting that many involved in the treatment of epilepsy are also involved in other areas of neurology. He would like to see more epileptologists trained and additional funding to make this happen. He noted large budgets in areas like MS and said that in Oman they are trying to be creative to obtain more support. He mentioned the EpiNet database for clinical trials (*P Bergin, New Zealand*) and his desire to create something like this in Oman and indeed the region. He suggested to the assembly that perhaps they could start with an educational course, particularly in paediatrics and noted that his attempts to start one in isolation in the past have failed, hence the need for regional co-operation and combined efforts.

S Wiebe offered that perhaps he could bring the '*ILAE/WHO Resolution on the Global Burden of Epilepsy*' document to his government, as some Ministries of Health (MOH) around the world have responded positively to this. He also stated that the ILAE can help in the translation of documents.

CC Triki stated that the EMR has fellowship training opportunities and that all Chapters are asked to create a course, which will be supported. She is ready to discuss budgets with any interested Chapters.

S Wiebe expanded on this by explaining that the ILAE gives the EMR an annual budget which, although finite, is available and ready to be accessed. Chapters need to approach and explain what they need.

H Cross added that the budget for the following year needs to be submitted by November of each year.

IRAQ

G Al Jandeel, Secretary General of the Iraqi Chapter, stated that for them finances are an obstacle. Physicians in the region have an expectation that industry will pay for their Congress participation, which can prevent attendance due to the low number of sponsorships available.

He noted that the physicians in Iraq are not aware of the ILAE or the EMR. Promotion will only go so far and he suggested that courses are conducted locally, for example in Baghdad, Damascus or Oman, and that the ILAE is introduced via this method. It will have a bigger impact and is preferable to Congresses which require travel and incur difficulties in obtaining visas. His efforts to obtain a visa to come to this Congress in Marrakech required much planning far in advance. Four of his colleagues wanted to come but could not get a visa.

E Perucca agreed and stated that perhaps the region could mimic the migrating courses that Europe has been organizing in its Eastern regions. This may remove many of these obstacles and he also noted that they are cost effective. CC Triki added that they are currently attempting to do this. H Cross stated that paediatric training has been extended to countries in the region and they are planning to translate these courses into French. Interactive workshops are part of the program along with lectures that encourage a 'two-way' dialogue.

S Wiebe suggested that, given the success of the migrating courses elsewhere, a significant part of the EMR budget be allocated to similar courses. E Bertram opined that a central 'course office' could be put in place for the League that would work like the Congress office, to look after the admin while the work is done locally. S Wiebe agreed.

R Al Youbi stated that within YES they had heard from young people who attended a course recently in Dubai and how successful it had been. She noted how easy it is to access this city and suggested it be used to hold courses.

LIBYA

N Barakat introduced himself as the person who facilitated the establishment of the Chapter in Libya. He agreed that training is important and also added that a database on patients should be created as this will help both the patients and the physicians. This can then be used to approach governments to improve their health services. Every country has its own training budget within its health ministry and suggested that everyone try to tap into that. With improved communication this can be achieved.

S Wiebe reiterated that the budget be refined and that courses be rotated where nearby countries can benefit. However, he warned that running a course is 'work' and even when budgets are allocated, organisers can fail when they realise how much work is involved.

H Hosny stated that the ILAE does have a curriculum which the EMR can tap into. For example, Egypt, Tunisia and Morocco are interested in the same topics and could arrange a training initiative. The ILAE and EMR standardize courses which could then be put on the website for promotion. It won't cost a great deal.

CC Triki asked everyone to consult the website where announcements are made. She also asked Chapters to tell the EMR Executive about their national Congresses so they can be announced on the website.

E Bertram posed another question: for whom do you want the courses and how do you get information to them?

E Perucca asked the YES representatives how they plan to contribute to what is being discussed. How are they planning an effective network in these countries?

YES

A El Kady stated that there are not a lot of epileptologists in their region. Young people want basic courses dealing with emergencies in different languages. One-day courses would be most effective that can be targeted at emergency doctors/family doctors/neurologists/epileptologists.

H Cross gave an example of the PET 1 course as a one-day course for anyone who comes into contact with a seizure. Manchester and Liverpool would run one. She asked if the EMR could think about standardising material and emulating this model.

BAHRAIN

A Al Jishi from Bahrain opined that migrating symposia are excellent. The region is lacking in these and he noted that MS is 'streets ahead'. Companies are not interested in epilepsy so it is now the role of the ILAE to subsidise such symposia.

- One or two days are enough
- He suggested targeting students, family and general physicians along with neurologists
- In Bahrain they held two symposia with huge attendance
- Workshop on how to read EEG
- Workshop on video EEG

Next, he suggested that a good way to grow EMR Chapters is to use 'key leaders' in every country who handle national logistics. He is such a person in Bahrain and can contact the MOH.

S Wiebe highlighted examples in Latin America and Asia, where speakers local to the course location are used. In addition, schools and hospitals host the courses which are often inexpensive, if not free, negating the need for expensive hotels. He reiterated what H Hosny previously stated, in that the ILAE has a curriculum ready to be used and further suggested that an accreditation be used to attract attendees. He noted that there was sufficient momentum in the room to make this a reality.

SAUDI ARABIA

R Al Baradie, President of the Saudi Arabian Chapter, stated that in her country and in the Gulf, a

'Gulf League' was created for the purpose of organising training. Combining resources from several countries decreases the burden on one country alone. A migrating conference is organized as a result, having been held in Oman in 2019 and Kuwait in 2018. The Chapters have found it very helpful.

Saudi Arabia holds many very short, low budget courses in different regions of the country. She gave an example of one happening currently in the Mecca region which involves local teachers. In more remote regions, they use fewer teachers to keep costs down.

SUDAN

A Abdelrahman thanked the EMR for inviting him and stated that Sudan has submitted its Chapter application and is currently awaiting a response. He pointed out that in Sudan prevalence of epilepsy is on the rise, with a three-fold increase in the last ten years alone. Diagnosis is improving but they do not have enough epileptologists and as such, neurologists and paediatricians are engaged. Nevertheless, there is a scarcity of manpower and affordable medication given that modern AEDs are too expensive. Sudan lacks education and needs more courses. It hopes to be accepted as a Chapter so that it can work more with the EMR and also to help in the organisation of courses.

E Bertram suggested that the EMR aim to reach more than just epileptologists. One- or two-day courses may be too much for some physicians and an alternative is to prepare a one-hour lecture. This obviously won't make anyone an expert, but will raise awareness and pique some people's interest. The topic could be 'status epilepticus' for example and perhaps a standard one-hour lecture on this could be prepared for the region.

A El Kady stated that the difference between wealthy and poor countries in the region means that a standardised courses may not be the most effective. The structure could be standardised, but the content should be adapted depending on the location. CC Triki and H Cross agreed. He suggested the creation of a course for treatment in countries with poor resources. H Cross also offered that the use of different content diminishes lobbying power.

S Wiebe stated that there is a lot of benefit in having a course(s) that is face to face to create awareness. He suggested not limiting attendance to a certain type of professional.

R Al Youbi stated that YES is ready to start.

N Barakat asked what is the criterion/opportunity for Chapters to nominate fellowships. CC Triki replied that last year there were four fellowships; young people with a background in epilepsy were chosen and there is a preference for neurologists/child neurologists. Preference is also given to those working in government with pending plans for a project. In 2019 there were eight applicants with an age limit of 40 years. Nevertheless, there are not as many applicants as they would like, and therefore more money can be used for other kinds of training instead. She highlighted that female doctors in Tunisia cannot go away for a few months and suggested e-learning.

S Wiebe stated that the ILAE already plans to launch this in 2019 which will be through English.

CC Triki added that it's easier to identify people for fellowships at face to face courses.

PALESTINE

A Misk stated that there are few drugs authorized in the region and that better contacts with the

MOHs are needed. He is such a contact in Palestine. MOHs are focusing on MS and Stroke with Epilepsy falling behind. In addition, he has found in Palestine that in daily practice, some physicians are unable to treat. He also suggested that it is the role of everyone present to use the media, TV, radio, to talk about epilepsy.

ALGERIA

M Djellaoui said that in Algeria the problems are the same. An absence of data, no medication, no courses, poor education of neurologists and paediatricians. In addition, there is a lack of education of patients and the general population. Algeria has made attempts to address this by:

- gathering data and investigating the prevalence of epilepsy in the country
- three teaching courses in different regions using national practitioners
- establishing contacts with the associations of patients to make the lobbying efforts more effective for medications. It helps to open doors for the population to participate.

E Bertram suggested sending the media stories on people where epilepsy could have been avoided. For the 110th anniversary the ILAE is writing to the Health Ministers to make them aware of epilepsy and introduce them to their Chapter Presidents. It doesn't always work, but in some places it has. The goal is to bring each Chapter into contact with its Health Ministry. Letters will be sent to each Chapter shortly; some people have said this is not useful and we respect that. Nevertheless, it will work in some countries.

M Fredj suggested the creation of regional courses to avoid issues of visas much like the Maghrebian or Gulf courses. When guidelines have been created then these can be used to approach governments.

S Wiebe opined that guidelines be adapted to suit local situations. The ILAE has experience in this and he highlighted the amount of work involved. He offered the support of the ILAE in the creation of such guidelines pointing to a task force that can help.

CC Triki asked all present to send her their ideas for courses and the EMR Executive can then put these into its budget.

S Wiebe stated the next steps should be:

1. Plan another meeting, preferably by Zoom. CC Triki asked for this to happen every three months, which will enable everyone to get to know each other better. Friendships will help the situation improve
2. Create inexpensive courses, where waiting for budgetary approval is not necessary

MOROCCO

R Ouazzani Taibi stated that in Morocco there is no service for epilepsy in the MOH and that they have a desire to develop a centre. He asked that for communication purposes, the ILAE does so in French, Arabic and English.

Next, he asked that low income countries are given better access to cheaper fees at Congresses. The salary in Morocco is US\$300 per month which is the cost of one registration. The Congress needs to cover the cost of breakfast and lunch. When fees are high like they are at the East Mediterranean Congress, Moroccans prefer to go to European congresses.

CC Triki asked everyone to send their list of members so that it can be used to source speakers. She will send an email to all requesting this and asked for full participation.

She closed the meeting and thanked everyone for attending.