INTERNATIONAL
EPILEPSY NEWS

ISSUE 1 - 2019

FUTURE STRATEGY REVIEW

VICE PRESIDENT ELECTIONS

INTERNATIONAL GOLDEN LIGHT AWARDS

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EPILEPSY NEWS
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FROM THE EDITOR

This latest issue of International Epilepsy News brings you a detailed report of the Strategic Review meeting that took place in London in January. With participants including members of the International Executive Committee and stakeholders from every IBE region, this successful meeting now provides a clear pathway for the future.

One of the main issues discussed in London was the need to identify IBE's future leaders and the importance of focussing on young people in this task. The International Golden Light Awards, which will be presented for the first time at the congress in Bangkok in June, recognises and applauds eight young people who have not led epilepsy prevent them from attaining their goals. You can meet them in this issue.

We also bring you the results of the recent IBE elections to fill the seven Regional Vice President positions for the next four years. The successful candidates will begin their four year term at the time of the General Assembly in Bangkok.

Also in this issue we share with you news of the IBE President's visit to Chile; a major investment that the Australian government has promised to epilepsy; a report from Japan and an unusual jazz restaurant; as well as a report from Cameroon on efforts to encourage people with epilepsy to seek appropriate care and treatment. Happy reading!.

Ann Little
Editor

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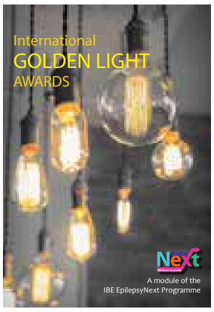

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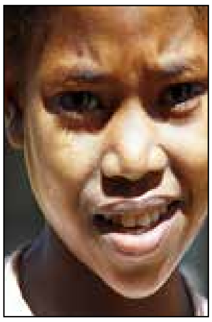

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PRESIDENT'S MESSAGE

DEAR FRIENDS

As I write this latest message to you, we are reaching the midway point of the current Management Board's term of office. This we will celebrate during the General Assembly at the 33rd International Epilepsy Congress in in Bangkok on 25th June. I do hope that many of you will be able to attend to hear about progress to date and to share with us your thoughts on IBE's future directions.

It was with the latter in mind that we organised a full day meeting in London early in the year to review IBE's current strategy, drafted in 2015, to see whether it was still fit for purpose and to agree on how best it should be adapted to address recent societal developments. Attending the meeting were members of the IBE Board as well as invited stakeholders from each IBE region. The good news is that, to a great extent, we are on the right path. We do, however, need to pick up speed and adjust our steering a little in order to avoid potential pitfalls.

One of the key changes will be greater focus on young people, who will be the next leaders of IBE. We have already begun this process with the EpilepsyNext program.Those of you who will be in Bangkok will have the opportunity to meet the eight amazing young adults who will receive the first IBE International Golden Light awards. The call for nominations resulted in 30 young people being put forward from across all seven of our regions. Not surprisingly, it was very difficult to choose the winners. All nominees shared their personal and moving stories of how epilepsy had impacted on their lives. The eight selected will present their stories at a special session in the Bangkok congress, scheduled to start at 13:00 on Saturday 22nd June. Each winner will be then formally presented with their award later that evening during the opening ceremony.

In early March, we celebrated the 5th East Mediterranean Epilepsy Congress in Marrakech. While delegate numbers were a little lower than anticipated, the congress provided an excellent program with scientific, medical and social issues being addressed by a panel of local and international speakers. For IBE, the highlight was the special day for people with epilepsy and their caregivers. I was delighted and humbled to meet many attendees from the region who, despite some perceived issues with their health services, had not lost hope for themselves and their families.

More recently, in April, I accepted an invitation from the IBE chapter in Chile, ANLICHE, to speak at their annual epilepsy symposium with more than 150 specialists coming together to discuss a range of advances in epilepsy diagnosis and care. During a less formal session, I had the opportunity of meeting a number of young doctors to discuss the diagnosis and management of epilepsy. The highlight of the visit to Chile was time spent at the workshop school run by our IBE chapter, which offers vocational training for young people with epilepsy and special needs in cooking and catering. This is an inspiring and practical venture, providing employment skills for the students so that they can become valued members of society. Their enthusiasm, confidence and self-belief was obvious to all. I spent the rest of the day meeting the people involved in running this impressive organization.

By the time you read this succint review, the World Health Assembly (WHA) will be in full swing in Geneva. An important session at the WHA will be a side event hosted by nine countries at which the Global Report on Epilepsy will be launched. This is a joint initiative of the World Health Organisation (WHO), IBE and ILAE. A huge amount of thanks is due to those chapters who encouraged their national ministers to support this project, which will provide an important opportunity to highlight the need to have epilepsy recognised as a health priority in every country in the world.

In closing, I would like to send my congratulations to our seven newly elected regional Vice Presidents, who will begin their four-year term of office at the time of the General Assembly in Bangkok.

With best wishes

Martin Brodie

President, IBE

LOOKING FORWARD

IBE reviews its Strategic Plan

In this modern fast-changing world, where innovation is key and where no idea remains new for long, the need to adapt is key to providing the support and services that IBE chapters deserve. Recognising the importance of regular reviewing where we are and where we need to be is vital. With this in mind, in January, IBE held a meeting in London to review the strategic plan already in place and to consider the changes needed to ensure that its future direction continued to be in line with its core mission. The meeting was attended by a number of invited stakeholders representing people with epilepsy and their care-givers, along with the members of the International Executive Committee. Noémi Ambrus, a professional consultant from Hungary, facilitated the event. Here you can read the full report.

Introduction

In preparing for the meeting, Noémi Ambrus had held telephone interviews with a number of stakeholders and a wider group had also been invited to participate in an online survey. From these activities, five pertinent issues had been identified as requiring discussion, to ensure that the IBE's future strategy was fit for purpose:

1. Roles and responsibilities of board members
2. The difference between a 'working board' and a 'governance board"
3. Patient involvement and representation in IBE
4. Changes in the current strategy

On the day of the meeting, and in advance of considering the current strategy and considering how well this had been implemented, each participant was asked to share their expectations for the workshop. Some of the comments expressed included:

- To have a clear view on strategies
- To establish a concise 'doable' plan
- To implement what we plan
- To agree on 'the basic things'
- To generate genuine engagement of stakeholders
- To establish a plan of action
- To set priorities
- To have a common theme implemented across all IBE regions

- To strenghten activities at the grass-root level
- To establish clarity of role for IBE
- To introduce a funding plan and the best practice to do so

General Discussion

It was generally agreed that the current Strategic Plan (2016-2019) was still relevant but required an implementation plan. The current plan identifies goals but does not include the 'who, how, when' nor does it identify a budget to achieve the goals.

The facilitator stated that boards should review their strategic plan at least every six months to measure progress towards implementation and this is something that IBE is taking on board for the future.

It was also stated that with 1.2 full-time paid staff, the board needed to be an active hands-on 'working board' but was currently operating as a 'governance board' without any direct involvement in day to day operations.

A discussion about staffing needs of the IBE followed and the following considerations were raised:

- Should IBE consider hiring a paid fundraiser?
- Could we identify existing projects that are attractive for funding?
- How can we reduce the burden on our Executive Director?

It was agreed that the Executive Director should identify tasks that could be completed by an assistant and to create a job description for this role. It was aso agreed that funding should be allocated so that the Executive Director could hire an assistant to lessen her workload.

The board was advised that it should be mindful that it had legal oversight and responsibility for IBE and needed to know that there is an expectation that board members will provide time and treasure to the organization. Board members should consider what value they bring to the board in respect to IBE's goals and objectives.

IBE should also consider including people on the board with specific expertise: communications experts, fundraisers, human resource professionals, lawyers, chartered accountants, etc.

The Treasurer has responsibility for fiscal oversight and our lack of oversight puts the organization at risk. The group then discussed the financial position of the IBE and the need for a diversified sustainability plan. It was agreed that there is a need for a clear dual objective: that of the internal operational plan and the external priorities of raising awareness, and how it is important not to neglect either.

The group discussed Jim Collins' model for organisations, which is based on Mission, Capability and Funding, and how sustainable operations are needed in all three areas. Our organisation needs to increase our sustainability which is small. In order to do this the organisation needs to grow its capacity first, and acquire funding which will than enable capability. A business case needs to be developed to result in support.

It was proposed that the board identify 'working groups' and that board members

be encouraged to join a working group or appoint people from their region to a working group. Four groups were proposed: Stakeholder Engagement, Sustainability, Capacity Building and Communication. It was also suggested that Youth Engagement be made a priority.

The group went through each of the goals of the current strategic plan to identify how they aligned with the proposed leadership groups.

There were 3 goals that need to be revised by the executive committee:

1. Promote the prevention of epilepsy
2. Promote access to currently available treatments
3. Promote the value of research and new therapies to stop seizures and cure epilepsy.

The following was proposed:

1. The Executive Director would be a member of each working group and would oversee the progress of the strategic plan.
2. The Chairs of each working group would be invited to join the IBE Executive Committee, where this was not already the case.
3. The Chairs of each working group would form a leadership team with the IBE Management Committee. They would meet on a regular basis and would provide accountability for the implementation of the IBE Strategic Plan.
4. It was agreed that the current strategic plan would be extended to cover the period 2019 - 2023.

Stakeholder Engagement Working Group

Members Francesca Sofia (Italy) Chair Italy, and Carol D'Souza (India), agreed to be members of this group.

The terms of reference for the group and the addition of members will be decided by the chair at a later date.

It was proposed:

- That by 2023, a minimum of 50% of the board should be stakeholders (persons with epilepsy (PWE), care providers, staff of not for profit epilepsy organisations). It was noted that guidelines or byelaws needed to be drafted.
- IBE should look to develop advocacy training. This needed three separate approaches for chapters in high-, middle- and low-income countries and tailored as needed.
- Define 'who' are our stakeholders?
- People living with epilepsy need to have access to becoming a board member.
- Group to work together to develop a letter to explain a proposed engagement programme.
- An element of the engagement programme could be to develop a summer school to train stakeholders on how to be more engaged.
- That a list of possible outstanding "champions" would be drafted; people in the list would be contacted and asked to join the group. The Group will continue to monitor the stakeholder landscape over time, to find and involve more "champions".

It was agreed that the Stakeholder Engagement Working Group would be responsible for leading the implementation of the following strategic priorities:

- Advocate with WHO, UN to recognize epilepsy as a worldwide need and to aggressively pursue strategic global outreach – develop a global action plan for IBE advocacy and WHO in collaboration with partner organisations like ILAE.
- Encourage member countries to implement legislative and regulatory changes within each country to promote human and civil rights for people living with epilepsy, and report on progress to IBE.
- Encourage all chapters to include people impacted by epilepsy on their boards, in their planning and in their activities.
- Ensure that all international, regional and national meetings in which IBE is involved, include tracks for lay organisations, social services, and for people and families affected by epilepsy.
- Assist development of new chapters in areas that are not currently served.
- Encourage youth councils in member organisations.

Main photo, from left: *Athanasios Covanis, Past President; Mary Secco, Secretary General; Graeme Shears, Epilepsy Foundation Australia; Anthony Zimba, Treasurer; Satish Jain, VP South East Asia; Ding Ding, VP Western Pacific; Francesca Sofia, FIE Italy; Martin Brodie, President; Natela Okujava, VP Europe, Phil Gattone, VP North America; Carol D'Souza, India; Ann LIttle, Executive Director; Noémi Ambrus, facilitator; Youssouf Noormamode, Vice Chair Africa; Tomás Mesa, VP Latin America.*

Below: *Phil Gattone, Chair of the Sustainability Working Group makes a point during the breakout session*

Top right, from left: *Francesca Sofia, Carol D'Souza, Mary Secco and Ding Ding in discussion*

Bottom right: *plenary discussion, facilitated by Noémi Ambrus (back to camera).*

Sustainability Working Group

Phil Gattone (USA) Chair, Martin Brodie (Scotland),Youssouf Noormamode (Mauritius) and Thanos Covanis (Greece) agreed to be members of this group.

The terms of reference for the group and the addition of members will be decided by the chair at a later date but will include the following:

- Recommendation of whether to hire a resource development manager.
- Build a comprehensive case for financial support.
- Attractive projects for funding included Promising Strategies, EpilepsyNext, International Epilepsy Day, IBE website, etc.
- Identify donors and a process for solicitation.
- Encourage chapters to identify large donors, 10% of any donation raised in a region could be provided to the chapter.
- Idea to develop a 'Friends of IBE' group.

The Sustainability Working Group will be responsible for leading the implementation of the following strategic priorities:

- Seek support to allow lay organisations and people with epilepsy to attend IEC meetings or regional meetings
- Evaluate dues and means of financial support for IBE and make recommendations for changes to improve IBE's financial status, sustainability and independence.
- Create representative inter-regional and cross-regional task forces for each IBE goal to foster inter-organisational mentoring, best practice exchange, and to support the development of action plans and recommendations on standards and strategies for action for regions, for countries, and for IBE.
- IBE and all its chapters have the opportunity to meet electronically at least 2x a year through resources such as Webinex or GoToMeetings or Skype

Capacity Building Working Group

Graeme Shears (Australia) Chair, Satish Jain (india) and Anthony Zimba (Zambia) agreed to be members of this group.

The terms of reference for the group and the addition of members will be decided by the chair at a later date but will include the following:

- What capabilities is IBE missing?
- Who are the members of the IBE?
- Look at staffing
- Look at volunteer recruitment and mentoring
- Ways to involve PWE at all levels up to board membership. Board members should have skills and reason to commit.
- Is IBE 'for' people with epilepsy or 'of' people with epilepsy?
- Epilepsy Foundation in Australia had a project template that could be adjusted to suit IBE's requirements. This would be circulated.

It was agreed that the Capacity Building Working Group would be responsible for leading the implementation of the following strategic priorities:

1. Encourage each chapter to support making epilepsy a health priority within their respective country, and encourage mentoring within regions to promote epilepsy as a public health priority.
2. Encourage and incentive each IBE member country to report on progress on strategic global outreach targets

to IBE and regularly share information with WHO and others on progress.

3. Create and share model legislation and guidelines with IBE chapters, and offer mentoring to member countries form those who have successfully made impact.
4. Encourage regions to identify epilepsy-focussed human and civil rights goals for their member organizations.
5. Ensure that all international, regional and national meetings in which IBE is involved, include tracks for lay organisations, social services, and for people and families affected by epilepsy.
6. Create representative inter-regional and cross-regional task forces for each IBE goal to foster inter-organisational mentoring, best practice exchange, and to support the development of action plans and recommendations on standards and strategies for action for regions, for countries, and for IBE.
7. IBE and all its chapters have the opportunity to meet electronically at least 2x a year through resources such as Webinex or GoToMeetings or Skype
8. Establish a mentoring program where chapters offer to provide information exchange.

Communications Working Group

Mary Secco (Canada) Chair, Ding Ding (China) and Carol D'Souza (India) agreed to be members of this group.

The terms of reference for the group and the addition of members will be decided by the chair at a later date but will include the following:

- Develop a communications strategy
- Identify people with communications skills – e.g. pro bono support from ad agencies, PR companies for social media campaigns, stakeholders who are professional communicators
- The WHO Epilepsy Report will be a valuable document for communications.
- A clear professionally developed message was needed
- A style guide needed to be developed (use of terms: epileptic, patient, lay organisation, etc.).
- Consideration of a Stigma task force
- 'Understanding Epilepsy in the World' research group

It was agreed that the Communication Working Group would be responsible for leading the implementation of the following strategic priorities:

1. Advocate with WHO, UN to recognize epilepsy as a worldwide need and to aggressively pursue strategic global outreach – develop a global action plan for IBE advocacy and WHO in collaboration with partner organisations like ILAE.
2. Encourage and incentive each IBE member country to report on progress on strategic global outreach targets to IBE and regularly share information with WHO and others on progress.
3. Share and promote accurate, up to date information about the impact of epilepsy in different regions, its treatment and its consequences through website, newsletter, conferences
4. Provide accurate information exchange on evidenced based best practices in self-management of epilepsy, epilepsy in schools, youth and young adult programs, and other identified programs through face to face meetings, digital platform (website), newsletter, and other identified means.
5. Promote the use of electronic and social media to inform and exchange information, as well as to create communities among people affected by epilepsy.
6. Ask member countries and community partners to link to IBE website and track growth in participation.
7. Encourage chapters to pursue awareness and education campaigns about current concerns of epilepsy, prevention, need for better treatment for those affected.
8. Utilize electronic platforms for meetings within regions and cross regionally to promote information exchange and to support the creation of collaborative learning groups.
9. IBE and all its chapters have the opportunity to meet electronically at least 2x a year through resources such as Webinex or GoToMeetings or Skype

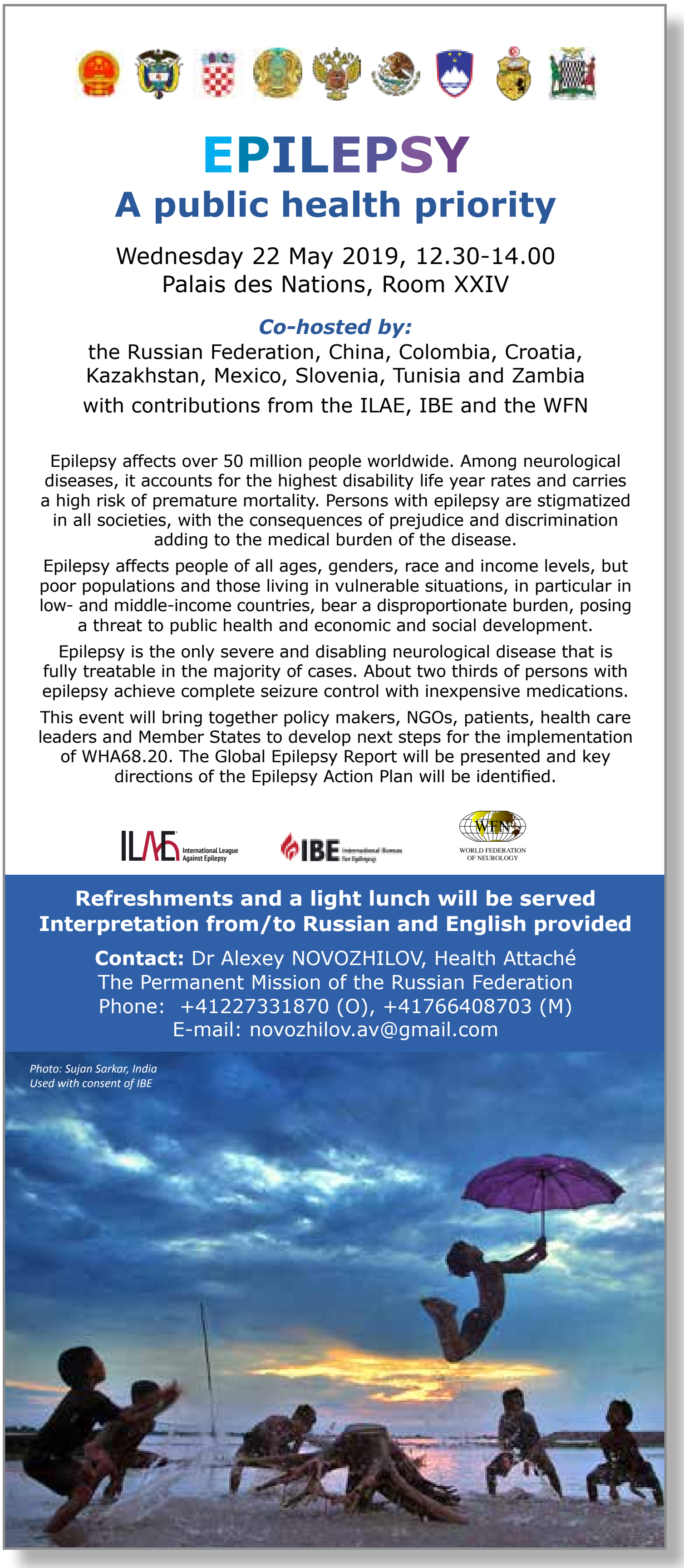
Facilitator's Recommendations

1. Strategy document should be on the website – transparency is key
2. The group should communicate about the meeting to the chapters and wider audience
3. In order to engage others, a description of background, focus and aim for each working group needs to be developed and posted on IBE website.
4. Job descriptions were required for each working group and staff position.
5. Exposure of IBE could be helped through aligning with human rights groups – disability, discrimination and NCD groups.
6. For financial stability the organization needs 4 types of income with no more than 50% funding from a single source. It also needs a reserve of 6 months in the bank at all times.
7. It is necessary to develop an action plan as donors will not give money to fund the operations of an organisation.
8. The Board needs to include more champions/people living with epilepsy.

33rd
International
Epilepsy Congress
Bangkok, June 22-26, 2019

IBE General Assembly
Tuesday 25th June 2019
16:00 - 18:30
Bangkok Congress Centre
WE HOPE TO SEE YOU THERE!

BRINGING THE EPILEPSY MESSAGE TO THE 72nd WORLD HEALTH ASSEMBLY



EPILEPSY

A public health priority

Wednesday 22 May 2019, 12.30-14.00
Palais des Nations, Room XXIV

Co-hosted by:
the Russian Federation, China, Colombia, Croatia, Kazakhstan, Mexico, Slovenia, Tunisia and Zambia
with contributions from the ILAE, IBE and the WFN

Epilepsy affects over 50 million people worldwide. Among neurological diseases, it accounts for the highest disability life year rates and carries a high risk of premature mortality. Persons with epilepsy are stigmatized in all societies, with the consequences of prejudice and discrimination adding to the medical burden of the disease.

Epilepsy affects people of all ages, genders, race and income levels, but poor populations and those living in vulnerable situations, in particular in low- and middle-income countries, bear a disproportionate burden, posing a threat to public health and economic and social development.

Epilepsy is the only severe and disabling neurological disease that is fully treatable in the majority of cases. About two thirds of persons with epilepsy achieve complete seizure control with inexpensive medications.

This event will bring together policy makers, NGOs, patients, health care leaders and Member States to develop next steps for the implementation of WHA68.20. The Global Epilepsy Report will be presented and key directions of the Epilepsy Action Plan will be identified.

Refreshments and a light lunch will be served
Interpretation from/to Russian and English provided

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Photo: Sujan Sarkar, India
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Message from the Co-chairs ILAE/IBE Global Outreach Task Force

Dear Friends

Preparations to the Epilepsy side event at the 72 WHA (72 World Health Assembly) are well advanced. We are pleased to inform you that the participation of the WHO leadership, Dr Svetalana Akselrod, NCD Assistant Director General, has been confirmed and the WHO Director-General, Dr Tedros, is also planning to attend our side event. The Executive Summary of the Global Epilepsy Report will be presented at the event.

It is strategically important to ask the Health-care authorities, representing your country at the 72 World Health Assembly, to attend this side event. As you can see from the invitation above, the epilepsy side event is scheduled for lunchtime on May 22 in Room XXIV of the Palais de Nations in Geneva. The program for the event will be finalized soon.

As a reminder: the application for the official side event “Epilepsy - a public health priority” has been submitted by the Russian Federation, co-sponsored by China, Colombia, Croatia, Kazakhstan, Mexico, Slovenia, Tunisia, Zambia and supported by the ILAE, IBE, WFN (World Federation of Neurology).

Attendance at the side event by Member States is vital for its success and plays a very significant role in raising the profile of epilepsy as a public health priority. We hope that as many Member States as possible will be encouraged to participate.

Your support in this is greatly appreciated.

Kindest regards,
Alla (Guekht) and Mary (Secco)

INTERNATIONAL GOLDEN LIGHT AWARDS

Meet the eight young adults who have been selected to receive an International Golden Light Award at the 33rd International Epilepsy Congress in Bangkok in June.

We received a fantastic response to the call to chapters for award nominations.

As part of the process nominees were asked to write their story in 500 words and you can find many of these on the IBE website ibe-epilepsy.org. The judges were greatly moved by these stories and found it extremely difficult to selected the final candidates.

It was agreed that, while just eight people would receive an award, everyone nominated was a winner!

Nina Mago, Uganda

Having experienced the stigma and cruelty imposed on people with epilepsy by those who do not understand the condition, Nina created the Purple Bench Initiative Uganda. It povides people with epilepsy and their caregivers with a platform to share information and experiences. She is encouraging individuals with epilepsy to adhere to their drug regimes and creating awareness in order to reduce stigma towards people affected by epilepsy.

She is reaching out to primary schools to demystify epilepsy; equipping teachers with knowledge and skills in helping pupils who have epilepsy; addressing student nurses to empower them with practical skills to relate to the theory they are taught; and addressing Rotary Clubs in Kampala and Masaka.

Amirsoheyl Pirayeshfar, Iran

For as long as Amirsoheyl can remember, he has been taking medication for his epilepsy and his asthma too, but it has not stopped him from striving to achieve his professional and personal goals.

Growing up, Amirsoheyl developed a love for music playing guitar and harmonica, piano and violin and he now plays with an orchestras in Iran. He has combined his interest in research with his passion for music by studying how to control seizures with music and designing a bio sensor for music therapy; this led him to write a book entitled “An Introduction to Epilepsy Music Therapy”.

Amirsoheyl has had his scientific work accepted for presentation at many international conferences and has won awards at conferences for the standard of his papers.

Emma Lovise Larsen, Norway

Emma used to call the hospital her second home and had a lot of experience as a patient where the worst thing was never having anyone to talk too. She decided to be a spokesperson for those who feel alone, who feel like they have no one to talk to, who just need someone to understand them.

So she started a blog and took part in a book project, which told her epilepsy story. At the book release, she was encouraged to join the Norwegian Epilepsy Association.

One year later, she was sitting as a leader for the epilepsy federation youth Norway and writing for their blog. She was also sitting on the youth council at her local hospital. Her focus has always been positive - “I feel if your attitude is negative, everything surrounding your epilepsy will also become negative”.

Rebecca McGhee, Scotland

Epilepsy has given Rebecca opportunities to help and support others who are living with the condition and to help spread epilepsy awareness. She has lots of seizure types - tonic clonic, partial and absences - and living with epilepsy has made some things challenging for her. I’ve had loads of injuries, including broken bones, broken teeth and even a ruptured spleen! But she doesn’t, and won’t, let epilepsy stop her doing things.

She worked with Epilepsy Connections to help start a ‘Young Adults Support Group’, an online support group that keeps in touch most days and also meets up once a month for pizza. Rebecca also blogs about her epilepsy and has even volunteered to be part of a film project about epilepsy,

Sofia Betanzo, Chile

Sofia had her first seizure when she was 6 years old and then started to have many seizures each day. She has refractory epilepsy which is the most severe type, drug-resistant and does not respond to treatment. She takes a "cocktail" of drugs and has seizures every single day. She has a wonderful family and good friends who make her world a happy place, but not perfect. She has begun to document her life - the seizures at school, that many hospital stays because of falls and convulsive status epilepticus, the vagal stimulator implant and many attempts with alternative medicine such as Reiki, magnets and numerous others.

She believe that other children, young people and adults with epilepsy and their families, who have the same experiences with their epilepsy, could read her book and be empowered to handle them positively, just as she does.

Elizabeth Dueweke

Despite dreams of becoming a journalist, Elizabeth did not follow her dream on graduation, fearing that stree would negatively impact on her seizures. However, she took a graduate degree in public health and communications to combine her passion for telling stories with improving health for people with epilepsy. Her final project researched the perceptions of employers on employing people with epilepsy and presented the research at an American Epilepsy Society annual conference.

She is now manager of communications at Epilepsy Foundation in Washington DC.

"I report the accomplishments of people with epilepsy and their families, bringing. their stories out of the darkness and into the daylight. I never lost the dream or career I thought I could have. I just found the stories I needed to tell," she says.

Mohammad Agus Rohmatulloh, Indonesia

I have epilepsy, a physical disability and difficulty in speaking, but this has not stopped me from advocating for a better understanding of epilepsy in families, in communities and beyond. A support network is very important for people with epilepsy so, in 2014, a few friends and I created a community called JATIM ODE for people with in Surabaya to share experiences and to be able to talk openly.

Last year, I enrolled in the PROGRESSIVE programme; the support and advice from the JATIM ODE group was invaluable. I then got an internship with the programme and, through this, received an invitation to speak during Social Week at Airlangga University. Through my experience with JATIM ODE I was able to deliver the message that people with epilepsy should not be afraid and that they can still attain university education and work in the same jobs as everyone else.

Scarlett Paige, Australia

Two years after her first seizure in 2006, Scarlett's epilepsy was controlled following neurosurgery in Melbourne. This is where the Epilepsy Foundation of Victoria first made contact with Scarlett and she became a regular on their adult and women's getway weekends, flying from Tasmania to take part. She returned to work in early education and gained a diploma in Early Education and Care.

In return for the support she received from the Foundation, Scarlett and her mother took up the running of the Hobart epilepsy support group for two years. In 2015, she moved to Victoria and now volunteers there. "Being volunteer has been one of the most enjoyable things I have done. It has seen many highs and some very sad lows. But knowing that when you hear the diagnosis *Epilepsy* you are not alone , that there are people to support you every step of the way, makes the road less rough.

A visit to Fukuchi Society

Report by Ding Ding, IBE Vice President Western Pacific Region

The Healthcare Corporation, Fukuchi Society, in Japan was established exactly 20 years ago with the aim of providing a comprehensive care system for people with neurological disorders. I was pleased to accept the invitation of the society and visited there in August 2018.

Fukuchi Society is located in Nagoya in the centre of the country. It didn't take much effort for me to locate the Society by its address. It's a humble building, but it's neat and well arranged. The assistant explained to me that Fukuchi Society aims to advance an unprecedented method of recovery and rehabilitation through assistance with health, financial and household matters affecting people with a neurological disorder. During the last 20 years, Fukuchi Society has grown to include several facilities, which constitute the core of its recovery program. Fukuchi Society is unique for its commitment to assist people with neurologoical disorders to smoothly integrate into the society through the inventive programs it has designed such as day care, independent living, and employment training.

I was impressed by the daycare program, which was conducted by Suzukake Clinic and Fukuchi Clinic. I visited the daycare unit and found it to be a space for social interaction, peer support and mutual friendship among its clients through various tailored programs. Another facility is the Mental Health Support Center, which hosts a community support center and care home dormitory. By coincidence, I came across a meeting preparing for an upcoming activity in the neighborhood. The attendees were social workers and people with epilepsy, who routinely organize activities for members of the Society.

The third facility that constitutes as the core of Fukuchi Society is the Employment Transition Support Office, which is called Kuneru. This support office offers comprehensive job training for those who would like to take a leap and find work, thus becoming self-supportive. The facility includes two bakery shops and a live jazz restaurant both of which are run as ordinary businesses and yet serve as the initial job training venues for those who successfully complete the training course of Kuneru. Unfortunately, when I arrived at the Jazz Restaurant, business hours had not yet started. Two waiters welcomed me warmly. Although they were people with epilepsy, they were very happy to work there, enjoying serving others and working on their own. Seeing the Jazz restaurant with various instruments, I could imagine that this should be a wonderful place when music and dancing are in full swing every night.

At the end of my visit, the Society assistant also stressed that Fukuchi Society is committed to promoting epilepsy awareness in Japan as a part of its recovery program. Under the motto of "eliminating stigma and creating a system of realizing true social integration", Fukuchi Society has been, for years, active on building a happy society and bright future for people with neurological disorders.

Good Luck to Fukuchi Society. Next time I return, I hope to enjoy the jazz!

Photos:

- *Top: two staff members greet guests at the Jazz Restaurant.*
- *Below left: Jazz Restaurant exterior.*
- *Below: Ding Ding, 2nd from right with the volunteer staff of Suzukake Clinic, Fukuchi Society.*

REGIONAL VICE PRESIDENTS 2019-2023

ELECTION RESULTS

VICE PRESIDENT AFRICA

Action Amos, Malawi

I am the Founding Executive Council Chairperson of the National Epilepsy Association of Malawi. I led the organisation to a membership of 12,000 persons with epilepsy in four years. I am a seasoned Inclusion Advocate and Strategist for 13 years. I supported the Ministry of Health in Malawi to develop guidelines on epilepsy. I have a lived experience of epilepsy since I was diagnosed in 1992.

I am the Executive Director for the Federation of Disability Organisations in Malawi (FEDOMA) which is the Umbrella Organisations of 12 Disabled Persons Organisations in Malawi, including National Epilepsy Association of Malawi. I have an MBA in Leadership and Sustainability from UK, a BA in Development Studies from Ireland and a Postgraduate Diploma in Disability and Rehabilitation Management.

VICE PRESIDENT EUROPE

Natela Okujava, Georgia

Dr Okujava has been working as a neurologist/epileptologist since 1987 and is involved, not only in treatment, but also, in the lives of people with epilepsy and their families. This was a major reason why, together with friends and supporters, she launched the "Epilepsy and Environment" association in 1997, IBE's Chapter in Georgia. In 2017, she was elected Vice-chair of the IBE European Executive Committee. When Caroline Morton-Gallagher resigned from the position of Vice President in 2018, she was invited to assume the positison for the remainder of the current term.

VICE PRESIDENT EASTERN MEDITERRANEAN

Hassan Hosny, Egypt

Prof Hosny is Professor of Neurology at Cairo University. Trained at Cairo University Hospitals, he completed fellowships in Clinical Neurophysiology and Epilepsy at the University of Chicago and at Cleveland Clinic Foundation in the US. He is President of the Egyptian Epilepsy Association, the IBE chapter in Egypt, which he founded. He was elected on two occasions as Chair of the ILAE Commission on Eastern Mediterranean Affairs and is a former member of the Editorial Board of the international journal Epilepsy Research.

Prof Hosny was elected as Vice President Eastern Mediterranean Region for the term 2017-2019, and has now been re-elected to serve a further four years.

VICE PRESIDENT NORTH AMERICA

Phil Gattone, USA

Mr Gattone worked as Director of Education at Rush University Epilepsy Centre and led the Epilepsy Foundation in Chicago for several years before joining the Epilepsy Foundation of America, where he has served as President and CEO for the past 7 years, successfully increasing revenue and restructuring the organisation. He is currently IBE Vice for the region and has now been re-elected to serve another term. Personal experience as a father of a son who has endured thousands or seizures, multiple medications and two brain surgeries to control his seizures, has driven him to become passionate about creating a movement for change

VICE PRESIDENT LATIN AMERICA

Tomás Mesa, Chile

Prof Mesa is Associate Professor at Pontificia Universidad Católica de Chile (PUC); Director of Children's Section in a post-graduate training program for epilepsy; Director of Pediatric Sleep Training at the Sleep Medical Center and former Head of the Pediatric Neurology, Genetics and Metabolic Diseases Section. He is Past President of the Chilean League Against Epilepsy and the Association of Chilean Leagues Against Epilepsy (ANLICH) - Chilean chapter of IBE. He has served on the IBE Regional Committee for Latin America as Secretary (two terms) and as Vice President and Chair (since 2017).

VICE PRESIDENT WESTERN PACIFIC

Ding Ding, China

Dr Ding's career of epilepsy care began in 2002, as a co-investigator of a demonstration project in China, carried out within the framework of the ILAE/IBE/WHO Global Campaign. She has been involved with the IBE chapter in China since 2005 and set up the Sea Horse art club for people with epilepsy. She served on the Global Campaign Task Force and is currently Vice President for the region. She will now serve a further four-term.

MM Mehndiratta

India

VICE PRESIDENT SOUTH EAST ASIA

Dr Mehndiratta is Director, Professor & Head of Department, Department of Neurology, Janakpuri Superspeciality Hospital in New Delhi. He is currently Vice-chair of the IBE South East Asia Regional Committee and has been a board member of the Asian Epilepsy Academy. He is President-Elect Indian Epilepsy Association and is its current Secretary General.

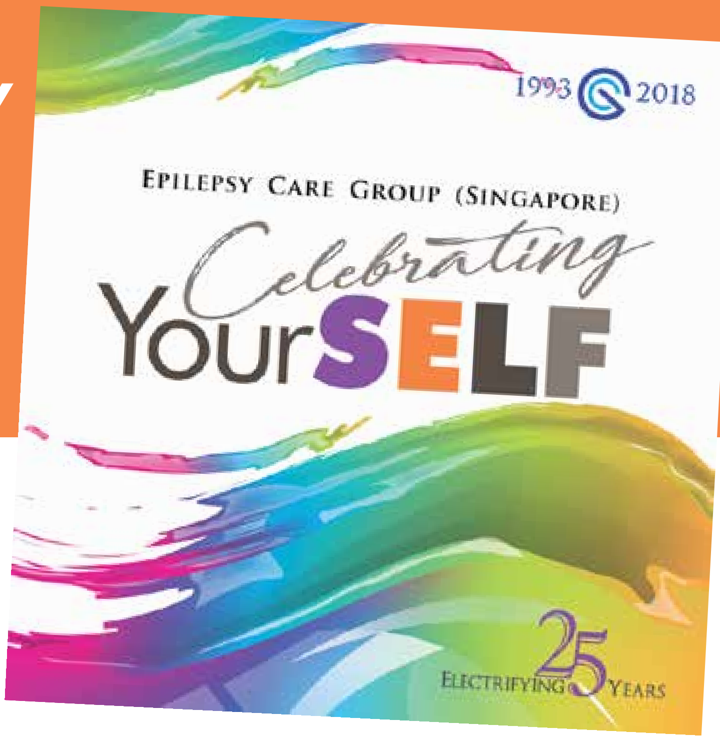
He has been a member of the scientific committee for several national and regional congresses and has spoken about epilepsy in the media. He is also currently serving as a member of the Executive Board of the ILAE-Asia and Oceania Committee.

Introducing the seven newly elected IBE Regional Vice Presidents, who will represent their regions on the IBE International Executive Committee for the term 2019-2023.

Their terms of office will begin at the time of the IBE General Assembly, taking place during the 33rd International Epilepsy Congress in Bangkok in June 2019.

ECG 25TH ANNIVERSARY CELEBRATION

Sherman Goh, Epilepsy Care Group, Singapore, reports



Epilepsy Care Group (Singapore) (ECG) held its 25th anniversary celebration on 23 November 2018. Blessed with cool evening weather after a short shower, the celebration held at the National University of Singapore Society Guild House was attended by a total of 100 people including guests, members, caregivers, and volunteers in addition to other members of the epilepsy community.

The first part of the event included ceremonial addresses by ECG President, Dr Choong Chew Thye, and ECG Founder Professor Michael Chee as well as a message from Mr Sam Tan Chin Siong, Minister of Sate from the Ministry of Social & Family Development. He concluded his message by hoping that ECG "will continue to inspire many more people to join and carrying out its good work with conviction and vigour." Also making a special presentation was a 10 year old girl with Benign Occipital Epilepsy who captured the hearts of the audience with her accounts of how she had raised awareness of epilepsy in her school by organising an event called, 'Pyjamas Day for Epilepsy' and raking over $1,000 for ECG. Students and teachers gave a $2 donation to wear their pyjamas to school. A cheque was then presented to the group's president. The audience was also captivated by the beautiful rendition of the song, 'A Journey of a Thousand Miles' by the winner of a song-writing competition as an initiative by ECG for this anniversary celebration.

Perhaps the moment that best captured the evening's spirit of celebration was the cutting of the birthday cake. Key members of ECG's executive council and a junior and senior person with epilepsy, together with the Guest of Honour created that momentous effect on social inclusion.

The second part of the celebration was enlivened by a performance by a hand bell group from a local church. The teamwork and unique harmony of the hand bell musicians was demonstrated by their outstanding performance of familiar Christmas carols and hymns.

That evening's celebratory note was wrapped up with a lucky draw, with twenty-five people walking away happily with their prizes.

We would like to thank everyone who helped in any way to make the day so special, and also to thank everyone who came. A member who turned up at ECG a few days later was dismayed to realise he had missed the event, but chuckled and said he would surely attend the 50th one! And indeed, we shall look forward to this member's participation in 25 years time!

ANNUAL DUES 2019

The call for chapter dues for 2019 is about to be circulated. Dues payments are important in funding IBE activities and in helping us support members in disadvantaged regions.

Dues may be paid in US dollars or in euro and we would encourage as many chapters as possible to pay in euro in order to reduce bank charges.

This is also a final reminder to those chapters with outstanding dues to settle any such payments as soon as possible in order to safeguard their membership status.

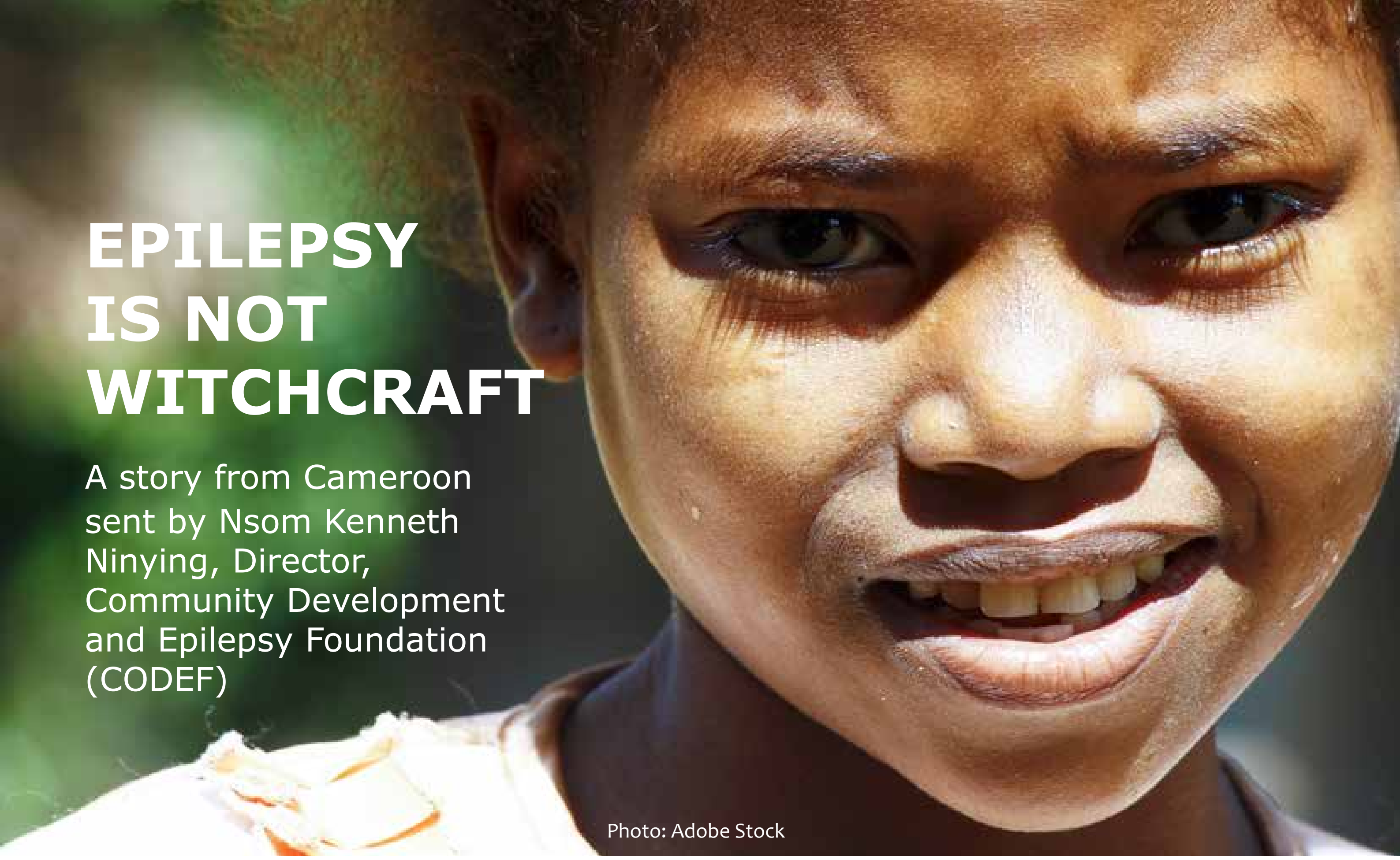
Did you know that you can pay by PayPal? PayPal can be used with any credit card and is the easiest method for both the payer and the payee. If you wish to use PayPal, please let us know and we will issue a Request for Money for this purpose.

The dues levels are:

- **Chapters: US$175/€150**
- **Associate Chapters: US$125/€105**
- **Subsidised rate: US$30/€25**
- **Provisional chapters: no payment**

More than 30 chapters based in developing countries continue to have their dues payments covered by the Solidarity Fund. When arranging your dues payment, we would earnestly ask that you consider a donation to the Solidarity Fund to help us to continue to support those chapters who have very limited financial means.

Contact annlittle@ibe-epilepsy.org with any queries on making a payment.



EPILEPSY IS NOT WITCHCRAFT

A story from Cameroon sent by Nsom Kenneth Ninying, Director, Community Development and Epilepsy Foundation (CODEF)

Photo: Adobe Stock

Mirabel Betala said her child was “thrown” by epilepsy. That she left her child with her sister to go for a job, but her sister remained with the child and started to be proud of the child.

“One day my child shouted, wet herself, her tongue came out, eyes turned, saliva came out of her mouth and that is how epilepsy was ‘thrown’ unto my child while she was still 5 years old,” said Mirabel.

“My child, who is 22 years old now, almost suffocated when she was six month’s pregnant and had a seizure, due to her epilepsy. Luckily, I was beside her when she had the seizures,” she added.

> Batibo and Wum in North West Cameroon and Ntui in the Central Region have very high epilepsy prevalence

A neurologist, Prof Elie Mbonda, says epilepsy is not witchcraft and it is not “thrown” on a person. Instead, Mbonda says that epilepsy is a kind of brain disorder that is chronic and cannot be transmitted from one person to another; and that epilepsy is treatable. Research in 1990 showed that, in Cameroon, some areas have the highest epilepsy prevalence in the world. And that of every 1,000 persons, 60 had epilepsy; now the number is reduced to 45 out of every 1,000. Prof Mbonda also said there is a change because the government and drug companies, assisted by Cameroon League against Epilepsy, is helping with treatment.

But Batibo and Wum in North West Cameroon and Ntui in the Central Region have very high epilepsy prevalence. In the 10 regions that comprise Cameroon, people with epilepsy are still likely to turn to traditional medicine. The League is collaborating with traditional herbalists/healers and with communities to educate them about the medical treatments available for epilepsy. Prof Mbonda said there is a high prevalence of epilepsy in Cameroon and how it manifests will impact on how it can be treated. For holistic care and management of epilepsy, traditional herbalists/healers and communities must all be involved.

Nsom Kenneth Ninying, Director of Community Development and Epilepsy Foundation, CODEF, says that in the rural communities of Batibo and Wum, in which the organisation works, many people have epilepsy. Kenneth explains that CODEF has been working in these areas, identifying persons with epilepsy, getting their health history, giving reports and statistics collected to Government District hospitals, forming epilepsy groups, and assisting them with income generating activities (IGAs) to help persons with epilepsy and their families to afford medication or go to hospitals. Kenneth added that CODEF also treat the injuries incurred by persons with epilepsy who fall and are bruised or burned due to a seizure.

He adds that CODEF educates schools and churches on how to prevent epilepsy. When someone in the community suffers a head injury, CODEF will accompany the person to the hospital, or ask his family members to do so, to be checked since head trauma is a cause of epilepsy.

Kenneth also says that working in the community, CODEF sees that women and girls are mostly affected by epilepsy while in Wum in the North West the Mbororos or Fulani people are the most often affected. Research is needed to identify why it is that this indigenous group in Cameroon has a higher incidence of epilepsy.

A visit to Chile

Keryma Acevedo reports on a visit by IBE President, Martin Brodie to the IBE chapter ANLICHE

The Chilean League against Epilepsy is committed to improving the quality of life of patients with epilepsy and their families. Over the years our institution has worked to educate the community in order to reduce stigma, teaching about epilepsy and collaborating with doctors' continuing education.

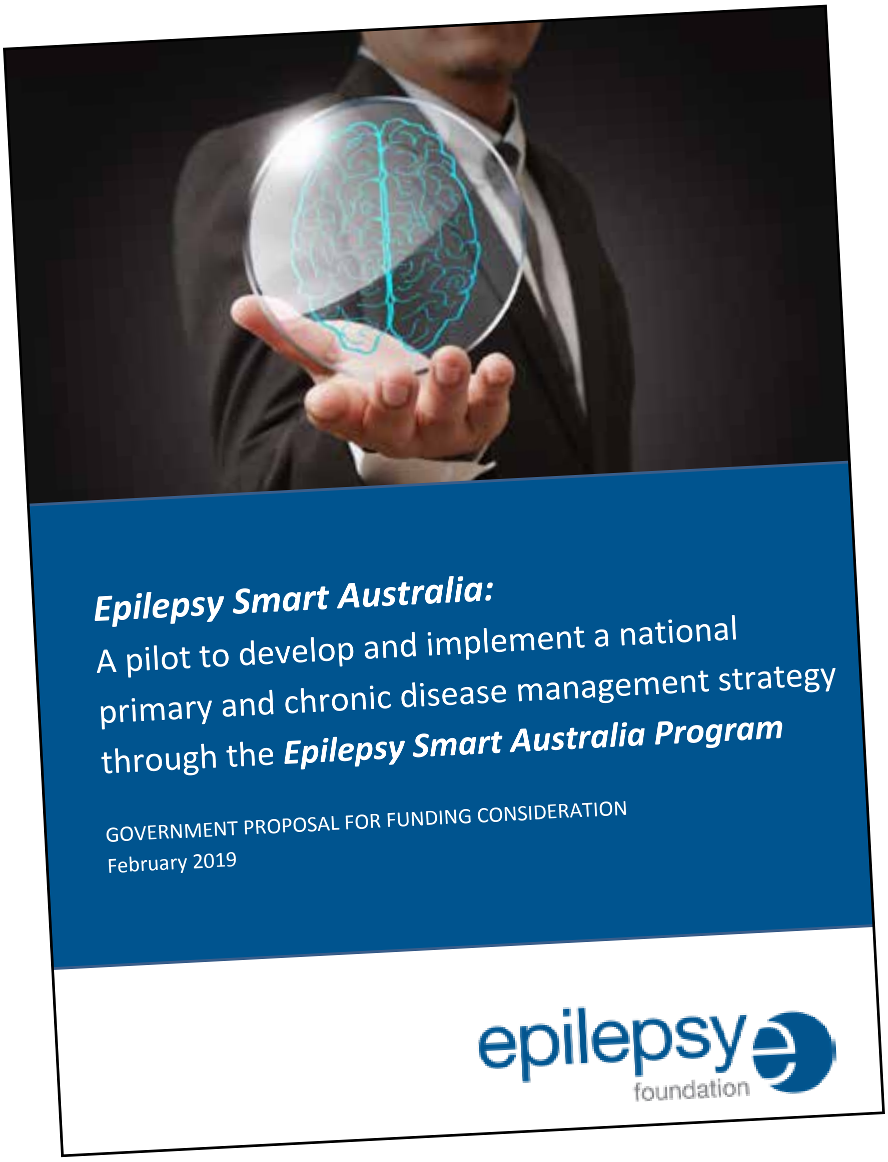
In April this year we organized, in Santiago, our 10th International Symposium: *Epileptic Encephalopathies and Autoimmune Epilepsies*, with more than 150 specialists from all over the country congregated to discuss the advances in these areas presented by national epileptologists and international speakers: Dr Rima Nabbout (France), Dr Sarosh Irani (England) and Prof Martin Brodie (Scotland).

Of remarkable interest was the seminar that Prof Brodie had with neurology and pediatric neurology residents which was an outstanding opportunity to discuss clinical cases, coordinated by Dr Alejandro de Marinis, President of the Chilean League against Epilepsy and Dr Tomás Mesa, IBE Vice President for Latin America. It was a relaxed meeting that allowed young doctors to learn about epilepsy from experienced doctors who encouraged them to participate.

Finally, Prof Brodie, who is President of IBE, visited our premises, the "Escuela Taller Dr Alfonso Asenjo", where teenagers with special needs and epilepsy go to school and attend to different workshops where they are trained in skills such as cooking and catering. The teenagers were in charge of lunch and coffee breaks while Prof Brodie held meetings with the Executive Board, volunteers and workers of the League.

EPILEPSY SMART AUSTRALIA

Government promises 20 million dollars to epilepsy



Epilepsy Smart Australia:
A pilot to develop and implement a national primary and chronic disease management strategy through the ***Epilepsy Smart Australia Program***

GOVERNMENT PROPOSAL FOR FUNDING CONSIDERATION
February 2019

epilepsy foundation

Epilepsy affects about 250,000 Australians with 1.25 million indirectly affected. This number is expected to grow in the coming years people live longer and more acquire this chronic condition. To help address this problem, the Australian Coalition Government has recently commited AUD 20 nillion, over four years, to support people living with epilepsy.

The funding will enable an expanded delivery of a range of national epilepsy initiatives that will reduce the chronic health impacts experienced by Australians of all ages living with epilepsy through a new program called Epilepsy Smart Australia. The national program will ensure people with epilepsy have access to information relevant to their age and condition, that workforces understand epilepsy and appropriately respond to the needs of workers living with epilepsy; ensure children in schools can achieve a better education; and reduce demands on hospitals.

The program, which has been developed by the Epilepsy Foundation, will be delivered by Epilepsy Australia, the national coalition of state and territory-based epilepsy service providers. Epilepsy Foundation is an IBE Associate Chapter, while the Epilepsy Foundation is IBE's Full Chapter in Australia.

Graeme Shears, Chief Executive Officer of the Epilepsy Foundation welcomed the funding announcement. "People with epilepsy, the Epilepsy Foundation and our Epilepsy Australia partners thank the Minister for Health, the Treasurer and the Coalition Government for its vision in giving us the opportunity to make Australia 'epilepsy smart'."

Joseph Azoulay, Chair of the Epilepsy Foundation said, "This is an opportunity for a whole-of-government investment in a much-needed, nationally consistent program that will enable more efficient and better delivery of practical services to people with epilepsy."

Wendy Groot, President of Epilepsy Australia, said the impact of epilepsy is a significant burden on Australia's health care, social services and human services.

"The cost to the community is significant in direct costs associated with diagnostic investigations, surgery, hospitalisation and rehabilitation, as well as indirect costs due to disabling side-effects, unemployment and premature mortality."

"This package will reduce that burden, enabling people of all ages who are living with epilepsy to achieve the best possible outcomes, whether they are children getting an education, people managing to obtain and keep a job, or older Australians receiving the support they need. People with epilepsy will be able to live safely and feel connected to their community," she said.

The Epilepsy Foundation has already established its Epilepsy Smart programs in Victoria including Epilepsy Smart Schools an initiative designed to educate teachers about epilepsy and management of students' epilepsy in the classroom, while creating awareness of epilepsy within school communities.

Epilepsy Australia is the national partnership of Australian epilepsy organisations across Australia – Epilepsy Foundation (New South Wales and Victoria), Epilepsy Queensland, The Epilepsy Centre (South Australia and Northern Terratories), Epilepsy Western Australia, Epilepsy Tasmania, and Epilepsy ACT.

International Epilepsy Day

MONDAY, 10 FEBRUARY 2020

CELEBRATED IN 120 COUNTRIES WORLDWIDE

www.internationalepilepsyday.org

After a very successful
International Epilepsy Day 2019,
let’s get ready for next year!