INTERNATIONAL
EPILEPSY NEWS
ISSUE 3 - 2018

YOUNG ADULTS MEETING SAN JOSÉ

Stories from Africa

VIDEO COMPETITION 2019

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FROM THE EDITOR

Although never intended, this issue could well be considered a 'Women's Special' because it contains the personal stories of a number of wonderful women who did not allow a diagnosis of epilepsy to hold them back. As Youssouf Noormamode puts it so well in his story from Rodrigues Island, Mauritius, it simply requires them to do it differently.

In the Mauritius story we meet two women who have achieved in their chosen fields; our follow up report on the Golden Light Award from Bali introduces two young women from Taiwan and China; while Edmund Cheong Henh Yew from Malaysia writes about his hero mother.

The issue could also be considered an African Special because of the number of articles focussed on the region. Or, yet again, an EpilepsyNext Special, because we report on events organised with young adults in mind.

We also bring you news of a video competition to celebrate International Epilepsy Day 2019 - we encourage everyone to take part!

Finally, on a sad note, we bring news of Augustine Mugarura's untimely death. Many in IBE will remember him with great fondness and be saddened at his passing.

Despite this final sad note, I wish you pleasant reading.

Ann Little
Editor

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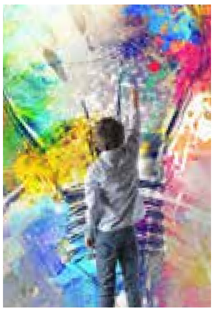

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PRESIDENT'S MESSAGE

DEAR FRIENDS

I have just returned from speaking at a meeting organised by our chapter in Georgia. I was delighted to be able to take the opportunity to see, at first hand, the tremendous work being undertaken at the Epilepsy Environment Association of Georgia under the stewardship of Natela Okujava, to support people with epilepsy in her country.

These efforts are a continuation of a demonstration project carried out under the banner of the ILAE/IBE/WHO Global Campaign Against Epilepsy some years ago and which is continuing in its collaboration with SEIN, one of IBE's associate chapters in the Netherlands. This is a clear demonstration of how chapters can support and work with each other on joint initiatives. I am aware that this has been happening on the African continent for some years, such as in Uganda, and I do believe there is great scope for further developing the concept.

In recent weeks, I was also a guest speaker at a conference organised by our chapter in Bulgaria, Association of Parents of Children with Epilepsy, on the kind invitation of Veska Sabeva, whose son has epilepsy and who has been a trojan worker in fighting for improved services for children with epilepsy in her country. It was fitting too that her work has been recognised in a special message sent by the President of Bulgaria.

These visits also give the opportunity to see at first hand the diversity of IBE's membership. On the one hand, this can be seen as a positive attribute in IBE's structure but, on the other hand, it does present us with challenges in identifying local initiatives that we should look further to develop elsewhere so that we can better focus meeting the needs of our membership worldwide.

This is something that we can consider when the International Executive Committee and a number of stakeholders drawn from each of IBE's seven regional committees come together in January in London to draft a strategic plan for the coming years.

As we near the close to the end of 2018 and look towards the New Year, we are planning events to celebrate International Epilepsy Day. I am sure that many chapters are doing likewise in advance of 11th February. Now well established since it was first celebrated in 2016, I am sure that International Epilepsy Day 2019 will be bigger and better than ever.

In closing, I would like to pay tribute to Augustine Mugarura, who founded and led our chapter in Uganda and who worked to improve the lives of people with epilepsy there for more than 20 years. His death, at the young age of 54, has been devastating to many people and a tragedy to his family, to whom I send my sincere condolences. May he rest in peace.

Until the next time!

Martin Brodie

President, IBE

COVER PHOTO

Young adults from the Latin American region who participated in the Young Adults Meeting, held under the banner of EpilepsyNext, that took place in San José during the Latin American Epilepsy Congress in October. Find out more on page 12.

EPILEPSY Next
IBE focus on youth

MEET TWO GOLDEN LIGHTS

Honouring young people with epilepsy who have been shining lights for others

One of the most potent means of shining a light on epilepsy is to hear the personal stories of people affected by the disease. With every diagnosis of epilepsy comes a unique set of circumstances and an altered future that affects not only the person with epilepsy but also their parents, siblings, parents and friends. The Golden Light Award honours young people with epilepsy who have been a 'shining light' for others and deserving of recognition.

First introduced in 2004, and formerly known as the Outstanding Persons with Epilepsy awards, awards have been presented at each Asian Oceanian Epilepsy Congress since then. The Golden Light Award recognises the fact that people with epilepsy should not be defined by their condition but, instead, embrace the call of the IBE to 'bring epilepsy out of the shadows and into the light'.

Over the years, the award winners have been given the opportunity at congress to share their stories of triumph over adversity, which IBE believes helps other people, struggling with their epilepsy, to grow in self-belief and confidence knowing that others have overcome sometimes very challenging impediments, not only to live quality lives but, often, to achieve great things. In the last issue of IE News we brought you the story of Katherine Height, the Australian mother of a young daughter with epilepsy. In this issue we feature the stories of the other two recipients of the award in Bali - Shuorong Huang, who comes from China, and Ern-Chun Hung, who lives in Taiwan.

Due to the success of the awards, IBE is now planning to roll out the awards in each region in which we hold a congress.

WHEN THERE IS A WILL, THERE IS A WAY

Shuorong Huang, PR China, pictured above wearing cream dress, with friends and delegates from China and Taiwn.

As I stand here today, it feels like a dream. However, this is different from my epilepsy nightmares. It is a beautiful dream come true. This surreal surprise is brought to me by charity work done for epilepsy. Finally I can smile and tell myself, "Li Shu, you are beautiful and you've made it."

My name is Huang Shuorong, or Li Shu as most people know me in China. Being a person with epilepsy myself for over 30 years, I went through countless agonizing treatments. Knowing that surgery won't necessarily cure me, I still decided to go for it because the suffering was just too much to bear. And with the slim hope I had, it turned out I was no luckier than any other patient. Epilepsy didn't disappear and this finally broke me. So much so that I was sufficiently despairing to consider giving up my life.

I understand now that a lot of my sufferings was because I did not have the right knowledge about epilepsy. My condition was not diagnosed at an early stage, thus proper treatments were not given in time. In the meantime, there is stigma about epilepsy and people like me are even humiliated at times. Suicide rates for people with epilepsy are 3-5 times higher than for others. And it's even up to 25 times higher for people with some types of epilepsy.

At this very difficult time of my life, a friend encouraged me. He said, "If epilepsy doesn't want to say goodbye to you, why not just accept it as a friend that lives like your own shadow. It reminds you every minute how you should be more passionate about life and embrace every moment that you are healthy."

It was an unforgettable 2006 for me. I finally gathered my courage to stand up and face life. I set up a blog called "Life with Epilepsy" to share my story on how I live and fight with epilepsy. To help people like myself, I started to provide friendly advice through phone calls and chat programs such as QQ and WeChat in China. I introduce basic correct knowledge about epilepsy and answer personal questions from individuals. My positive attitude gives patients hope and emotional support. Now more and more patients and their families come to me for consultations. In the past ten years, more than 390,000 people visited my blog, and I became an "internet star" on social networks. Through this, I also met the true love of my life. And I am blessed to have a girl and a boy with help from doctors.

In 2016, with the support of the China Association Against Epilepsy, the media and many caring businesses, I published a book called "Love in the days of Epilepsy" which is a compilation of the most frequently asked questions from the support service. All royalties from this book were donated to a social welfare foundation in Shenzhen China.

I believe that it is only through realizing personal values and being recognized by the society we live in that we can face life positively. In 2018, to help people with epilepsy to become financially independent and to create social values, I set up a non-profit online platform called "Eclampsia Home". It's an online shop that helps people with epilepsy to sell home-made goods.

For more than 10 years, I have received so much recognition, trust and support through charity work done for epilepsy. Epilepsy makes me suffer and once the world turned its back on me. However, it is also because of it that I am so involved with charity work which enables me to be embraced by kind hearted people in this world. This warms my heart.

Now I finally realize, when there is a will, there is a way. And when the light shines through that way, it's even brighter than one can imagine.

I HAVE EPILEPSY AND I AM PROUD OF MYSELF

Ern-Chung Hung, from Taiwan, pictured above left with colleagues at the Congress Opening Reception, tells us how she didn't allow bullying or embarrassment to prevent her establishing her successful career

I had my first seizure in kindergarten. My parents spent a lot of time caring for me and encouraged me to take music lessons, after they saw my passion for music. I have taken piano, flute, Zither and vocal lessons, and still play the piano and sing until this very day. Even though my parents loved me unconditionally, I was embarrassed because of my condition. I felt people looked at me differently and I was bullied at schools by other children and teachers. Kindergarten was supposed to be fun, full of laughter and friends, but there was no place for me.

After I started junior high school, I realized self-loathing only made things worse because I was not the only one suffering, my family and friends were upset and helpless to see me so unhappy. I decided it was time to change and began getting more involved at school, because I am the only one who can turn things around for myself.

In high school, I joined the school choir and enjoyed every second of it. Those three years were fun because I laughed a lot, had fun performing with friends; I was having fun. My music skills and dedication were recognized by other students and teachers. I was made deputy head of choir in senior year and started to develop my leadership skills.

My college major was a MICE (Business Tourism and Events Management) Degree Program and the dean was impressed by my outgoing nature so I was made class rep and gave speeches at various events. In junior year, I joined the Taipei City Information Center to help tourists and visitors and began my part-time job as Front Desk at a SPA resort. My action transformed myself and I am no longer afraid of the crowd. Currently, I am a Quality Assurance staff person by day and an EMBA (Executive Master of Business Administration) student by night and I thoroughly enjoy my prolonged student life.

At the weekend, I spend a lot of time with my loyal friends, playing piano and singing. Life treats my well and I am so grateful.

Looking back, the shy girl who felt worthless and was bullied so badly that she wanted to end her own life, has turned into an independent woman who has discovered the anchor of life and is dedicated to her goals. That girl is me!

I have epilepsy and I am proud of myself. My life is fun and enjoyable. When I am on stage, I express my feelings through music, I give speeches and share experiences. There are other wonderful things which I am grateful for; my student life, my friends who I can laugh and cry with, love and the attitude I have for life – a positive and love-yourself attitude.

Epilepsy is no longer an obstacle, it's a jumping stone to a journey of self-discovery.

Smile is a universal language and I hope my words carry it through and maybe even infections, so that the readers will start speaking the same language.

In memory of Augustine Mugarura 1964-2018

Obituary by Lone Nørager Kristensen, Chairman Danish Epilepsy Association and Kirsten Nielsen, Consultant, Danish Epilepsy Association

It's October in Uganda; it's 1997 and the rainy season has just begun. Eva - the then director of the Epilepsy Association in Denmark - together with we two, are seated under a mango tree on the small square in front of the church in Rubindi together with Augustine, Elias, who is a psychiatric nurse, and Deus, who lives with epilepsy.

We have just watched how seizure history was recorded and how the monthly supply of anti epileptic medicine was distributed by the psychiatric nurse. There were more than 100 people gathered, each one with the hope that the nurse would have time to help them.

Augustine was a social worker at Mbarara University Hospital in southwestern Uganda. Together with the small 3-man psychiatric unit, he had noticed a group of people who fell through the system and were difficult to reach because they lived in poverty and extreme stigmatization: people with epilepsy.

"When they cannot come to us, we must go to them!" was the thinking behind a new outreach concept that was launched by the small, underfunded psychiatric unit. And it was the beginning of a new area for people living with epilepsy in Uganda.

But Augustine saw immediately that medicine alone was not enough. To break away from the strong prevailing prejudices, myths and social exclusion that were associated with the symptoms of epilepsy would take personal strength and empowerment. Something that cannot be obtained at a personal level.

It was indeed a memorable meeting between Denmark and Uganda, those days under the mango tree in Rubindi. There was a deeper common understanding of epilepsy that easily bridged economic and cultural differences.

Augustine was quick to see how the experiences of the epilepsy association in Denmark could be adopted to fit a Ugandan context. Thus, it was Augustine who developed the ideas of what became the beginning of an association lead by people with epilepsy themselves in Uganda. The first ever user-governed epilepsy association on the African continent.

It was obvious that he should coordinate the project. In addition to being a social worker, Augustine was also a primary school teacher. He worked in the psychiatric unit during the day, did his Master's in Public Administration at night and moreover, he ran the project of getting people with epilepsy together to share their life experiences. When a nationwide Ugandan epilepsy association - Epilepsy Support Association Uganda (ESAU) - was born in 2004, Augustine became its director.

Augustine had in-depth political, social and economic knowledge of Uganda, from the poorest local area to the high-level ministries in Kampala. He used his analyzes when we put together strategies on how the new epilepsy association would develop. Augustine could create friendships and had a huge network. He opened his heart and family home to us and we became friends. He was always open to new ideas and journeys to Zimbabwe, Argentina and Denmark, among many other places, became very important to the way that Augustine developed the Ugandan epilepsy association over the years.

He held a number of positions of trust. Among others, he was a former member of the IBE African Regional Executive Committee and was a member of the IBE Research Commission at the time of his death.

Augustine had been the anchor and driving force of the ESAU for 20 years, when he was diagnosed with cancer in August and died at the relatively young age of 54 years on October 15th.

MY MUM IS MY HERO

By Edmund Cheong Henh Yew

My mum is my hero. She has epilepsy and has lived with it for 47 years. Her seizures are without warnings which means she can lose consciousness and fall down anytime. There were three seizures that could have ended her life. One seizure happened at the seaside in knee high water. She was rescued in the nick of time from drowning to death. Another seizure happened when she was crossing a busy street. She fell face down onto the side of the road and sustained severe injuries to her face. The third seizure happened when she was standing on the first step of a descending escalator. My dad managed to grab her in time and pulled her back to the top landing of the escalator.

My mum has defied many more odds associated with epilepsy. Despite it all, she makes sure her life is not lived in vain. She has never allowed epilepsy to limit her in her philosophy about life - “Nobody asked to suffer. They deserve to be helped”. In her first self-funded fundraising project in 1995, RM 260,000 was raised for an old folks home. She continued to initiate more self-funded fundraising projects for other charity causes right up to today. Altogether, she has been advocating about epilepsy for over 20 years. In recognition, the International Bureau for Epilepsy gave my mum an Outstanding Person with Epilepsy Award, the first ever given to a Malaysian. They also exhibited her epilepsy story in the European Parliament in 2015, which was the only Malaysian story. My mum is an inspiration to my family and my beloved country, Malaysia.

To celebrate Malaysia Day last September, Tesco supermarkets in Malaysia had a competition asking people to write about those they regarded as their heroes. Edmund’s story was one of the winners. His mother, Serene Low, tells us more.....

My world collapsed on me twice. The first was when I was officially diagnosed with epilepsy and the second was when my only son, Edmund was also diagnosed with epilepsy during his first year of university. Picking up the crumbled aftermath was closed to impossible. A patient myself I had become a caregiver to my son. From one storm to another it was extremely heart-breaking and painful when epilepsy dealt me with two mighty blows.

Perhaps it had to do with my own experiences in living and dealing with epilepsy that gave me the much needed strength, confidence and helpful knowledge to assist my son with his epilepsy.

A close friend told me that I ought to be thankful for having first-hand experience, information and knowledge on how to help out and make life with epilepsy easier for my son. In many ways I agreed with my friend. A harsh reality had set in. Nothing in the world could change it. With that in mind I was able to kick depression out of my life and living my life with more positivity was not as difficult anymore.

Serene and Edmund at the radio station

To celebrate Malaysia Day on 16th September, the Tesco supermarket chain in Malaysia invited people to enter a story sharing competition, with shopping vouchers going to the six best entries. Contestants were required to write about the people they look up to and why they regard them as their heroes. Edmund wrote about my epilepsy story, which turned out to be one of the six winning entries. We were both surprised and overjoyed as we didn’t think his entry would stand a chance since the competition was very stiff with lots of other entries submitted.

The win was to lead to an even bigger opportunity to raise awareness about epilepsy when a local radio station wanted to meet us in person to hear more about our story. All in all, a great result.

STRATEGIC REVIEW

As the IBE Strategic Plan 2016-2019 reaches its end date next year, a meeting to review the current plan and to draft a new strategy paper to address IBE's objectives for the coming years, will take place in London in January.

As well as the IBE International Executive Committee, the day-long meeting will involve a number of stakeholders representing people with epilepsy drawn from each of IBE's seven regions. In addition, a further number of stakeholders have been invited to participate in an online survey to ensure that the issues pertinent to each region are addressed.

The planning meeting will be facilitated by Kiry Noémi Ambrus, a professional consultant from Hungary.

The next issue of IE News will report further on this strategic review.

Just published

You can find the latest IBE Annual Report 2017 at https://www.ibe-epilepsy.org/publications/annual-report/.

The report contains a review of IBE activities last year as well as the audited figures for 2017 and a Contact Directory with details on committees, commissions and chapters.

ANNUAL DUES 2018

FINAL REMINDER

Does your chapter still need to pay annual dues for this year? Chapter dues for 2018 are now overdue. Dues payments are important in funding IBE activities and, if your association has not yet paid, it is important to do so as soon as possible.

Did you know that you can pay by PayPal? PayPal can be used with any credit card and is the easiest method for both sides. If you wish to use Paypal, please let us know and we will issue a Request for Money for this purpose. You can pay in US$ or in euro. The dues levels are:

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

INTERNATIONAL EPILEPSY DAY 2019

VIDEO COMPETITION

DEADLINE: 14TH DECEMBER 2018

International Epilepsy Day

AS PART OF OUR INTERNATIONAL EPILEPSY DAY CELEBRATIONS FOR 2019, WE INVITE YOU TO ENTER OUR VIDEO COMPETITION WITH CASH PRIZES FOR THE WINNING ENTRIES!

The winning videos will be selected based on their success in telling an inspiring personal story or in using a novel means of increasing knowledge and awareness of epilepsy. In each category, there will be one 1st Prize of US$500 and five Runners' Up prizes of US$100.

CATEGORY ONE:

My Personal Story

People with epilepsy, their families, friends and carers, can create non-professional individual short videos, using a smart phone or personal camera, to inspire others or to highlight problems faced.

CATEGORY TWO:

Educational Video

Open to organisations and support groups who have developed professionally produced videos to educate the public, policy-makers, and people with epilepsy themselves, about epilepsy during the past 3 years.

VISIT WWW.INTERNATIONALEPILEPSYDAY.ORG FOR MORE

Increasing public awareness and understanding of epilepsy and thereby reducing the stigma and discrimination that is caused by ignorance and lack of knowledge is crucial to improving the quality of life of people with epilepsy. With social media now playing a major role in the dissemination of information, short videos are an extremely effective means of telling a story, whether the video is made using a personal smart phone or as a professional production.

CONDITIONS OF ENTRY

Category 1:
My personal story, applicants must submit a video filmed on their own smart phone or other devise and must run for no longer than 2 minutes, including title and end credits.

Category 2:
A video must run for no longer than 2 minutes, including title and end credits.

Categories 1 and 2:
1. One entrant may submit a maximum of three entries in total to the competition. A separate entry form must be completed for each video submitted to the competition.
2. In the case where more than three entries are submitted, the first three entries received will be accepted (where the rules of the competition are met) and any later entries will be discounted.
3. Videos can use animation, real actors and be with or without spoken words.
4. Videos can be in any language. However, where the language of the video is not English, the video must include English subtitles.
5. Videos may not contain any offensive or inappropriate content, infringe on any intellectual property or other rights of any person or entity, violate any law or advocate illegal activity.
6. Videos cannot contain copyrighted music or images, unless there is authorisation to use them, or they fall under generally accepted fair use guidelines.
7. Videos may not endorse, advertise or otherwise promote any commercial epilepsy treatment or product.
8. Applicants must obtain the consent of any individuals appearing in the video if their faces are recognisable.
9. The copyright of materials submitted to the competition remain with the participants. However, by entering the competition, competitors give IBE and ILAE permission to embed the video link on the website of International Epilepsy Day.
10. Submission of an entry to the competition will be taken to mean acceptance of the competition rules.

IN BOTH CATEGORIES, THE VIDEO MUST RUN FOR NO LONGER THAN TWO MINUTES AND MUST BE UPLOADED TO YOUTUBE OR YOUKU (CHINA). ENTRIES MUST ALSO BE ACCOMPANIED BY A SHORT DESCRIPTIVE TEXT OF NO MORE THAN 100 WORDS

Submission:
1. The deadline for submission of videos to the competition is Friday 14th December. No entries received after that date will be accepted.
2. Entries must be submitted using the online ENTRY FORM.
3. Incomplete or late received entries will not be accepted.

X Congreso Latino Americano de Epilepsia
San José - Costa Rica 29 Sept - 2 Oct 2018

YOUNG ADULTS MEETING

SAN JOSÉ, COSTA RICA

My epilepsy gave me this opportunity!

So commented one of the young people who attended the 3-day meeting organised at the time of the Latin American Epilepsy Congress in San José. From El Salvador, Mexico, Chile, Brazil and, of course, Costa Rica, the final verdict of the participants was ‘Can we do this again, please!’. This comment was also echoed by the members of the IBE Latin American Regional Committee, who deemed the event to be a huge success and worthy of repetition at future Latin American congresses.

Special thanks must also go to Susana Lara Maier and Tomas Mesa Jr, who acted as facilitators over the three days.

With an upper age limit of 30 years, the objectives of the meeting were to provide young people with epilepsy with the opportunity to share their experiences of having epilepsy from both a medical and social perspective; to identify barriers, challenges and problems that hindered their inclusion in the community; and, as a group, to suggest guidelines to improve the lives of other young people with epilepsy.

The first two days of the workshop were devoted to a mixture of lectures and discussions on a range of topics and issues that impact on the lives of young people with epilepsy. This included issues such as exercise, relationships, education, legislation, lifestyles and mental health. The risks that people with epilepsy need to be aware of were also discussed. The most lively and interesting sessions took place on Day 2 when the young people focussed on epilepsy and the media! Throughout these two days, the participants met at the congress centre, attended the congress President Symposium, Opening Ceremony and Reception, and, as you can see, also took the opportunity to take some selfies!

On the second evening, the young people, for whom a small hostel had been rented, came together in the kitchen to prepare their

All photos courtesy of Susana Lara Maier

evening meal, in a party atmosphere (main picture). There was a mix of national dishes and personal favourites and a great night was had by all.

After the concentrated sessions on the first two days, Day 3 was a time for leisure with a tour of San José, some time for shopping, and the chance to relax and unwind. This day was just as important as the previous two, providing an informal fun atmosphere for the young people to get to know each other better and to talk freely about their lives lived with epilepsy.

When it was time to pack and travel home, it was clear that the event had been a tremendous success with strong bonds formed. There is a determination not to allow the momentum to drop, but to continue to work together to identify a project they can develop to address one of the problems identified over their three days together. From the point of view of the facilitators, it was clear that the young people were returning home more self-assured, confident and informed. Mission accomplished!

AFRICAN YOUTH SUPPORT

Poultry rearing among five projects to receive IBE funding support

Funds have been provided from IBE's general funds to support the establishment and sustainability of five projects, developed by young people in Africa, which aim to improve the situation for their peers living with epilepsy in Africa.

Earlier in the year, a call was issued inviting applications for projects that would meet the following criteria:

- The project must benefit young people with epilepsy between the ages of 18 and 35 years.
- Funds will be granted to projects with a duration of three and six months.
- Outcomes must be measurable and described in the application.
- The project should benefit a group of persons with epilepsy and not a single individual.
- The project should be implemented by young people with epilepsy who belong to the local IBE chapter.

Following the close of the call period and review of the applications received, five projects have been selected:

KENYA: 'Why me?" will raise awareness through social media and public talks

MALAWI: A schools project to reduce absenteeism caused by epilepsy stigma

SIERRA LEONE: Training in beadwork and lacework to assist in employment

ZAMBIA: poultry rearing training as a means of earning money and becoming self-sufficient

ZIMBABWE: "Shine like a star" a project to demonstrate the abilities of people with epilepsy, if given a chance to shine.

MEET NATELA OKUJAVA

Newly appointed IBE Vice President Europe

Following the resignation of Caroline Morton from her position at SEIN in the Netherlands, and her subsequent decision to look for a change of career path, the position of IBE Vice President Europe fell vacant. With less than a year to run in the current term of IBE's Regional Vice Presidents (the call for elections will begin in early 2019), the decision was taken by the IBE International Executive Committee to appoint Natela Okujava to fill the vacancy. Natela was already the elected Vice Chair for the region and will now combine both of these roles until the next General Assembly, which will take place in Bangkok next year.

Since graduating from university in 1987, Natela has been working in the field of epilepsy as a neurologist/epileptologist, with an interest not only in treatment, but also in the lives of people with epilepsy and their families. Together with friends and supporters, she created the national epilepsy association "Epilepsy and Environment" in 1997, which later became the IBE chapter in Georgia.

"The most important thing I have learned is strength of partnership. it always brings positive results for all parties and for a common goal. The Georgian association has partnered with SEIN in the Netherlands over a number of years and was involved in an ILAE/ILAE/WHO Global Campaign Against Epilepsy Demonstration Project that reported on a huge epilepsy treatment gap – 73% - and substantial levels of stigma," she explains.

Her plan for the European committee is to maximally effectiveness through coordination, planning and bringing different initiatives under one umbrella, as well as creating wider networks with other organizations in order to strengthen the voice of the committee.

As she moves on to pastures new, the International Executive Committee and Caroline's colleagues on the European Regional Executive Committee, would like to take this opportunity to thank her for her dedication and to wish her well for the future.

CONGRESS AWARDS BANGKOK 2019

Time is running out for chapters to nominate candidates for the Ambassador for Epilepsy and Social Accomplishment awards, which will be presented during the 33rd International Epilepsy Congress in Bangkok next June.

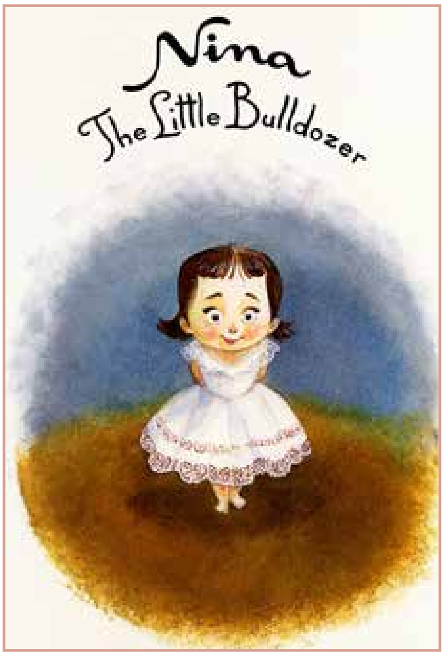
The deadline for nominations is 30th November.
For nomination forms or more information from annlittle@ibe-epilepsy.org.

Chapters may also suggest names for the IBE and ILAE Executive Committees to consider for the Lifetime Achievement Award.

NEW MEMBER TO EUROPEAN ADVOCATES GROUP

Epilepsy Alliance Europe, the joint initiative of IBE and ILAE in Europe, is delighted to welcome Tilly Metz MEP, from Luxembourg, who has joined the European Advocates for Epilepsy MEP group in the European Parliament. A member of Group of the Greens/European Free Alliance in the parliament, Ms Metz MEP brings membership of the European Advocates for Epilepsy group to 67.

Find out more at epilepsyallianceurope.org



NINA The Little Bulldozer

ninascourage.org

Nina, The Little Bulldozer is a short film that is part documentary, part animation. Through the words of Nadia and Thomas Davies (Nina's parents) the little girl comes to life and symbolizes the spirit of overcoming.

The short film was created by a group of talented individuals from Animation and Character Design Studios in Spain, France, Japan, and the US with music provided by an esteemed musician from San Francisco.

In four and one-half minutes you see epilepsy in a new light. The film simulates a seizure in an animated, artistic and compassionate manner and portrays the courage and hope of a little girl that in spite of her illness never gives up but just keeps battling on.

The artists worked free of charge to bring Nina's story to life in the hope that epilepsy might be better understood and accepted by the public, as have so many other diseases.

In addition to the film, Nadia Q. Davies has also written her daughter's life story. Normally prices at US$5.04, it will be available for free Kindle download from Amazon for 4 days during December. The book is called Nina's Courage in Epilepsy. You can find it at https://www.amazon.com/dp/B00EVVVO4U

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BAND AID

In Africa, approximately 10 million people live with epilepsy. While epilepsy can be a devastating and chronic condition, with basic treatment, more than 70% of cases can be controlled with one drug. Tragically, in Africa epilepsy is greatly misunderstood, deeply stigmatised, severely underfunded and, most often, ignored by the health care system. Over 75% of people in Africa with epilepsy live in rural and semi-urban areas where treatment is almost non-existent.

World Health Assembly Resolution

In 2015, the World Health Organization (WHO) General Assembly passed a landmark epilepsy resolution known as WHA68.20: Global burden of epilepsy and the need for coordinated action at the country level to address its health, social and public knowledge implications. This resolution is tremendously important in that it calls on all UN member countries to address epilepsy seriously by developing and implementing national plans of action.

Despite this global declaration, none of the countries in Africa has developed an epilepsy national plan. There has been no political response nor has there been any financial investments in programs that could reduce the epilepsy treatment and knowledge gap at the country level. Previous international agreements, such as the African Resolution on Epilepsy (2000), were never adequately implemented despite research in some countries such as Zimbabwe and Senegal, showing that the cost of managing epilepsy in resource poor settings was quite minimal.

IBE has chapters in 22 African countries. The size, financial and human resources of each chapter varies although their aims – to prioritise the social aspects of epilepsy and provide programs to dispel myths, reduce stigma and increase the seizure knowledge of persons living with epilepsy – are similar. A few chapters, such as those in Kenya, Zambia and Zimbabwe,

Providing IBE chapters in Africa with the tools to develop and execute country-specific national action plans

Ann Little, Executive Director, IBE; Mary Secco, IBE Secretary General and Co-chair of the IBE/ILAE Global Outreach Task Force; Jacob Mugumbate, IBE Vice President Africa

provide medical services such as diagnosis, treatment, mobile clinics and referrals. While the capacity of IBE chapters in Africa is limited, there is a strong desire to build their infrastructure in order to narrow the knowledge and treatment gap.

With this in mind, IBE approached the BAND Foundation and successfully secured US$65,000 in funding support for the creation of advocacy projects by five chapters in the IBE African region for the implementation of Resolution WHA68.20. The projects will be administered by the IBE African Regional Committee.

Work on this important initiative began in early July with a call to chapters to express an interest in the project, such interest to be indicated by the end of August. From these expressions of interest a final short list of five chapters will be created and projects are expected to begin by the end of 2018 and to complete within 12 months.

Project goals

The overarching goal of the BAND funded project is to reduce the epilepsy treatment gap and improve epilepsy knowledge throughout Africa. This goal will be achieved by providing IBE chapters in Africa with the tools to develop and execute country-specific national action plans and thereby implement the WHO Epilepsy Resolution (WHA68.20).

Funding and participating

For each country/chapter selected to be part of the project, funding will be provided to support the salary of liaison/advocacy officers and the development of workshops. The liaison/advocacy officers will receive appropriate training and mentoring, supported by a regional project officer and a regional project steering committee. The result of the project will see national associations build capacity, develop advocacy networks and work with national governments and health departments in the creation of national action plans for epilepsy.

By the end of phase one of the programme, the five selected chapters will have undertaken the following:

1. Identified the burden of epilepsy in the country context and identified key stakeholders who should be engaged.
2. Gathered information and conducted a situation analysis to obtain a clear understanding of the needs and resources available related to epilepsy at national level, and the coverage and quality of essential treatment. This will help identify any strengths and weaknesses in current systems and any barriers to expanding services.
3. Created an inventory of human, financial and material resources.
4. Engaged partners at the local, national and regional level for strategic linkages and collaboration. Such partnerships might include chapters of the International League Against Epilepsy (ILAE), disability groups, other NGO's, policy makers, elected officials, ministries of health, ministries of social development and the local and regional WHO office.
5. Formed a national coordination committee responsible for the development and implementation of an action plan with goals and timelines.
6. Created and adopted National Action Plans for Epilepsy.

Phase two will include implementation and monitoring of the 5 action plans at the country level. Additional sites will be recruited based on the successes, recommendations and pathways identified in phase one: Implementation of regional programs to reduce the knowledge gap; inclusion of epilepsy in government health care plans as well as government surveillance and data collection systems.

Key to the success of this initiative are the assumptions that the epilepsy knowledge and treatment gaps can be reduced through the development and execution of a well laid out national action plan, and that associations of people with epilepsy, their families, and professionals have a significant role in advocating for a national epilepsy plan to be developed, adopted and implemented.

ABOUT THE BAND FOUNDATION

The BAND Foundation is a private family foundation established in 1999 by Burks and Anthony Lapham and their children, Nicholas and David. It seeks to advance the family's charitable interests through strategic grant making, primarily in the areas of nature conservation, epilepsy research and climate change (the latter via an affiliated donor advised fund). The Foundation supports programs in the United States and abroad with a special emphasis on geographies with which the family has present or historic ties. BAND believes in a flexible, risk-tolerant approach to grant making, through which it seeks to provide timely support to critical issues, catalyse effective partnerships and unlock larger financial flows from public and private sources.

STORIES OF SUCCESS FROM RODIGUES ISLAND

Youssouf Noormamode from EDYCS Mauritius, shares the stories of two women who did not allow their epilepsy to hold them back

Rodrigues Island, a 108-square-kilometer autonomous outer island of the Republic of Mauritius in the Indian Ocean, lies about 560 kilometers east of Mauritius. It is part of the Mascarene Islands which include Mauritius and Réunion. It is of volcanic origin and is surrounded by coral reef, and just off its coast lie some tiny uninhabited islands.

The island used to be the tenth District of Mauritius; it gained autonomous status on 10 December 2002, and is governed by the Rodrigues Regional Assembly. The capital of the island is Port Mathurin.

Its inhabitants are Mauritian citizens. As of 2014, the island's population was about 41,669, according to Statistics Mauritius and there is an estimated 3,000 people with epilepsy living on Rodrigues. Most of the inhabitants are of mixed African and European descent. Its economy is based mainly on fishing, farming, handicraft and a developing tourism sector.

Often people with disabilities, especially people with epilepsy are discriminated against in the workplace. While there are laws in place to prevent this, the laws can-not change peoples' underlying perception of whether or not someone is capable of doing a job. In fact these ungrounded perceptions are mostly geared towards women with disabilities.

As many people with disabilities will tell you, their disability does not prevent them from doing things they aspire to. It simply requires them to do it differently. By starting their own business or hiking the pathway to their dream jobs, many women with disabilities have proven they can do whatever they set in their minds to and they can do it by creating their own rules.

That's the case for two women with epilepsy in Rodrigues, who overcame overwhelming misconceptions and stand on their own two feet while being financially independent.

Irenzie Edouard

In Rodrigues, we cannot talk about athletics without making reference to Irenzie Edouard. Aged 52 years, living in Citronelle, married and with two children. Irenzie Edouard was first diagnosed with epilepsy when she was 22 years of age, after which her seizures became recurrent.

However, her disability did not at all impede her from following her dream – that of becoming a successful athlete. She has won many competitions and proudly exhibits her medals and trophies. In fact she is reminiscent of Aimee Mullins - a below the knee amputee - who was the first woman to compete in the National Collegiate Athletic Association (NCAA) with a disability. She set world records in the long jump, 100- and 200-yard dash. She has artificial legs and, instead of viewing them as a hindrance, she views them as a benefit that allows her to do what she wants.

Besides her achievements in sports, Irenzie Edouard followed several training courses in crafts, gardening and entrepreneurship. Having gained her food handler certificate, she even embarked on cake baking, whereby becoming financially independent.

She has been seizure-free for the past five years and continues to show a high level of motivation, enthusiasm and commitment in whatever she does – thus serving as an example to young girls and women who want to achieve their goals in life.

Mary Joyce

Encompassing determination, diligence and courage, Mary Joyce, aged 41, who lives in Corail Petite Butte, is married and has two children sets an example for every woman with disabilities.

At a very young age, she was diagnosed with epilepsy. But this did not hinder her from leading a normal life. In fact, family problems and a depressed mode of life contributed a lot in her health instability. In 2016, she even went into a coma and was unable to speak after recovery. However, she underwent treatment and recovered her voice.

Having followed a training course in sewing and embroidery, she started her own business and emerged as a promising entrepreneur; today she receives orders from throughout Rodrigues.

So, while it was assumed that the term 'entrepreneurship with disabilities' was an oxymoron, nowadays thousands of people with disabilities are dispelling these myths by starting hugely successful businesses of every kind, just as Mary Joyce has done.

We cannot ignore the fact that women with disabilities are often faced with financial hardships. Nonetheless receiving the funds needed to start a business has been found to be a vital step in allowing them to focus on their goals instead of focusing on their disabilities. These women have shown that the factors leading people towards success is determination and an unwillingness to give up.

> **Their disability does not prevent them from doing things they aspire to. It simply requires them to do it differently**

A TIME FOR CELEBRATIONS

The William Quarrier Scottish Epilepsy Centre marks its fifth anniversary

Congratulations to the William Quarrier Scottish Epilepsy Centre (WQSEC), celebrating the 5th anniversary of its world-class assessment and diagnosis facility in Glasgow. Part of the IBE associate chapter, Quarriers, this is the only residential assessment and treatment centre in Scotland for adults with epilepsy.

At the anniversary celebrations, Eleanor Ferguson, mother of former patient Rachel Ferguson who was born with a learning disability, spoke at the event about the transformative effect the service had on her daughter. When Rachel was admitted she had very limited mobility, following close observation specialists at the WQSEC recommended introducing a new medication and significantly reducing another drug.

Eleanor said: “The improvement in Rachel’s condition is miraculous. She is now walking upright, her face is alert and animated again and the drooling and tremor in her arm has stopped. People who know Rachel can’t believe the difference.

“She has far fewer seizures and is now much more active and has built up her strength. She has more energy and is able to enjoy being out in the evenings again. She can even walk up to two-and-a-half miles with support, and enjoys swimming and trampolining. Above all, she is able to enjoy her life again.”

Head of Service, Gerard Gahagan, said: “The epilepsy that our patients live with is the most complex to treat or diagnose and their condition is often accompanied by significant co-morbidities and additional support issues, including learning disabilities. It is vital that Scotland has a service that is dedicated to this.”

About Quarriers

Quarriers is a Scottish charity providing practical care and support for vulnerable children, adults and families who face extremely challenging circumstances. Its services support adults and children with disabilities, young people facing homelessness, families facing poverty, unpaid carers and people affected by epilepsy. The charity runs over 100 services across Scotland.

***Photo:** back row - Gerard Gahagan, Head of Service Gerard Gahagan; Joanne Hill, Epilepsy Specialist Nurse; Bil Scott, Patron of the centre. Front row: Eleanor Ferguson, former patient Rachel Ferguson, Alice Harper, Quarriers Chief Executive; and Elaine Blackley, Senior Administrator and former patient.*

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