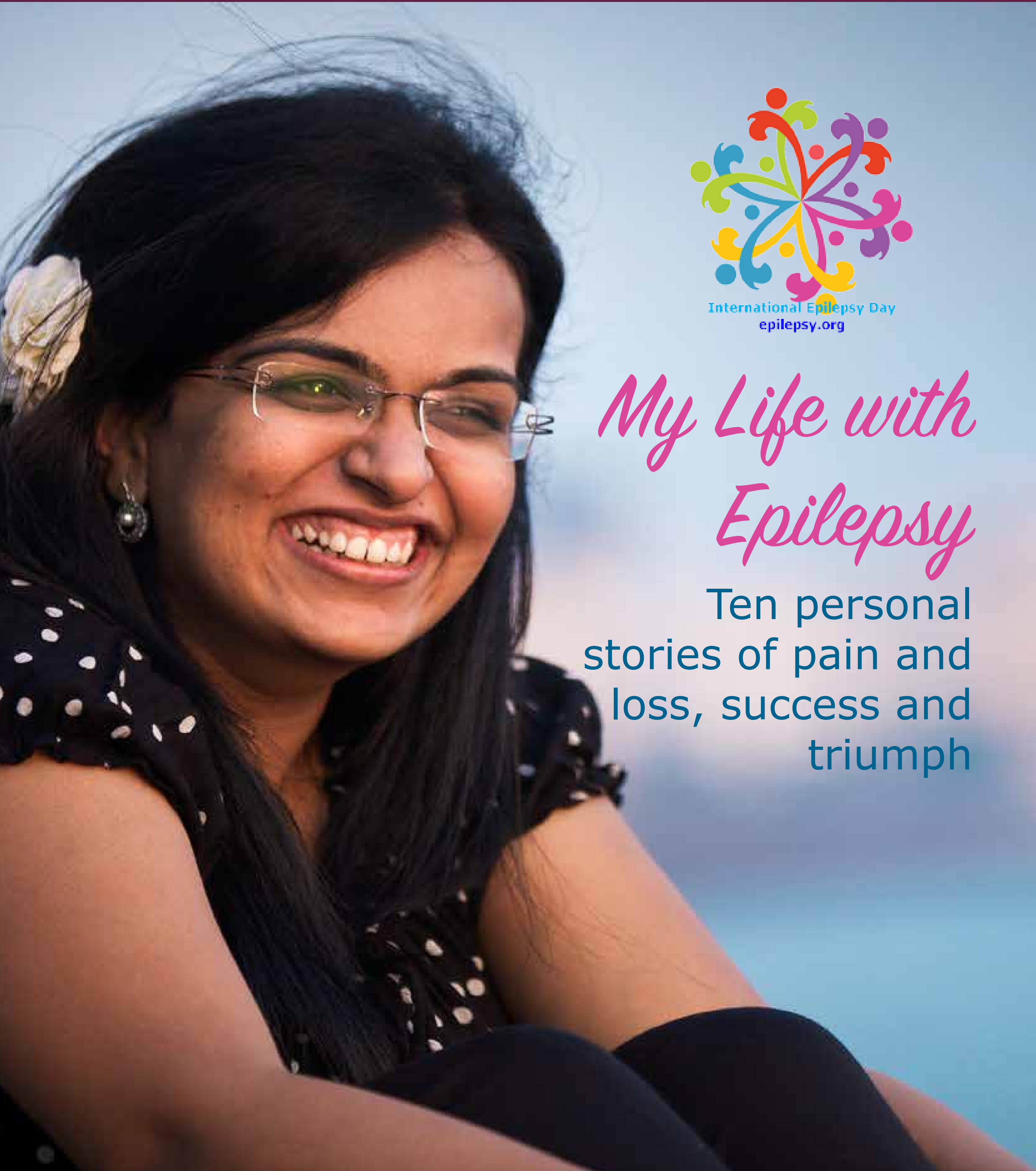
SPECIAL ISSUE CELEBRATING INTERNATIONAL EPILEPSY DAY 2015

INTERNATIONAL
Epilepsy News

Reporting epilepsy news for **52** *years*

1963-2015



International Epilepsy Day
epilepsy.org

My Life with Epilepsy

Ten personal stories of pain and loss, success and triumph

PRESIDENTS' LETTER

A Day of Celebration

Dear Friends

Standing together, we are delighted to send you a joint message of greeting on this great occasion as we celebrate the launch of the first International Epilepsy Day. For people with epilepsy, their families and carers, this is a new opportunity to share experiences and stories with a global audience and, thereby, to increase knowledge and understanding about epilepsy. In doing so, there is the chance to build a stronger epilepsy community, and a fairer world, for the 65 million people around the world who are living with the disease.

International Epilepsy Day provides a platform to lend a global voice to people with epilepsy, a disease that can have devastating consequences, affecting all aspects of the lives of people with epilepsy. These are our most powerful advocates, and their stories, showing bravery in the face of advertisy, demonstrate clearly that epilepsy is much more than seizures.

International Epilepsy Day is also a major step forward in raising awareness and improving the lives of people with epilepsy throughout the world. Its establishment is synergic with the approval, on 2 February, of the first WHO resolution on epilepsy by the WHO Executive Board in Geneva. The resolution, a true milestone, calls for a coordinated action in all member States to improve epilepsy care, to protect the civil rights of people with epilepsy and to increase investment into epilepsy research.

International Epilepsy Day is a day for all stakeholders and, as we celebrate this great occasion, we wish you every success in the events you have been planning to hold in your hospital or clinic, in your epilepsy association, in your school or workplace, or even as a personal endeavour, to mark this special day.

With best wishes from both of us,

Athanasios Covanis
IBE President

Emilio Perucca
ILAE President

IBE
International Epilepsy News
Special Issue

EDITORIAL TEAM

INTERNATIONAL RELATIONS AND PARTNERSHIPS

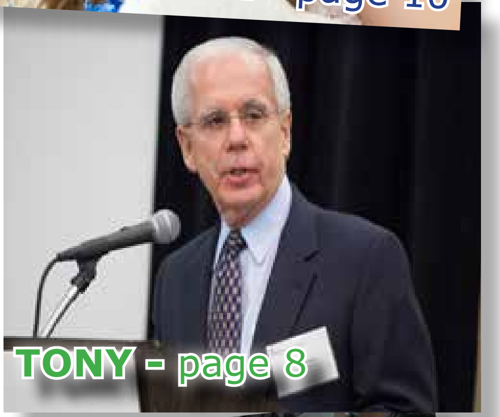
WHO
IBE is in official relations with the World Health Organisation (WHO).

ECOSOC
IBE enjoys Special Consultative Status on the Economic and Social Council of the United Nations (ECOSOC).

CoNGO
IBE is a member of The Conference of NGOs in Consultative Relationship with the United Nations CoNGO.

EFNA
IBE is a member of the European Federation of Neurological Associations (EFNA).

In this issue



Dear Readers

The Day has finally arrived and, after some years of discussion, several months of planning and a few weeks of frantic final preparation, International Epilepsy Day will unveil on Monday 9 February.

In recent weeks Social Media has been building momentum on #epilepsyday and it is great to see such enthusiastic support for The Day. Many of you are planning to take part in the #epilepsyday 'selfie' photo event and I look forward to seeing all the photos on Facebook, Twitter and Instagram.

In order to highlight that this is a combined effort of IBE and ILAE, for the first time we have a joint message from the Presidents of both organisations in our magazine, with Thanos Covanis and Emilio Perucca pictured outside the WHO Executive Board Room in Geneva on the day WHO approved a resolution on epilepsy, on which you will hear much more in the coming days and weeks.

However, today we give the platform to those people who can speak most eloquently about epilepsy - people with epilepsy themselves - and 10 awe inspiring personal stories are featured in this issue.

The magazine also includes news on some of the events taking place around the world to celebrate International Epilepsy Day.

Until next time - happy reading.

Ann Little
Editor

Coming in the next issue

REPORT

International Epilepsy Day
epilepsy.org

THE LOGO

A design representing togetherness

It's not always easy to find a logo that lends itself to a campaign, is bright and attractive and also tells a story. Yet that is exactly how to describe the logo for International Epilepsy Day.

We took a novel approach in getting our logo by introducing a Logo Competition. Why? Because, in this way we were sure that we would also be able to promote awareness about epilepsy and spread the word about International Epilepsy Day.

And it worked. The entries received to the competition were tremendous and it was very difficult to decide on a winner but the judges were agreed that the logo submitted by Mas Gustian was bright, colourful and symbolic.

Mas Gustian told us that the human silhouettes in the design represent togetherness and a common goal to care for, and to understand, people with epilepsy.

'The different colours represent the fact that people of all ages are affected by epilepsy and we must accept it and embrace its diversity," he explained.

He is a student at Gadjah Mada University, Yogyakarta, with philosophy as his major subject.

"Philosophy teaches me to have a positive and open mind to make a positive change to the people around me."

Art is his real interest, though, especially graphic design and branding and this is the area in which he would like to become professional.

His knowledge of epilepsy came from his young schooldays, when a classmate has epilepsy. Although initially frightened, he and the other students learned about the disease and knew what to do when a seizure occurred. Mas Gustian picks up the story:

"There are responsibilities for us to understand what epilepsy is, to give people with epilepsy support – not just material support but also spiritual and moral support.

"We must educate ourselves about epilepsy and sharpen our sensitivity, so that we are more attentive to people with epilepsy. I hope that my logo will inspire us to, hand in hand, provide social support and improve our understanding about what it is like to live with epilepsy".

epilepsy.org

The GO TO place for information and support documents

- **The EPILEPSY is more than SEIZURES poster available in more than 23 different languages**
- **Cover and Profile images for Facebook and Twitter**
- **Information on International Epilepsy Day events around the world**
- **Epilepsy First Aid information**
- **General Information on epilepsy**
- **Press materials**
- **Epilepsy Association contact details by region and country**

International
Epilepsy Day

PRESS RELEASE

Launching International Epilepsy Day

65 MILLION people around the world live with epilepsy

International Epilepsy Day will launch around the world on Monday 9 February 2015. Organised by the **International Bureau for Epilepsy (IBE)** and the **International League Against Epilepsy (ILAE)**, International Epilepsy Day will provide the platform for people with epilepsy to share their experiences and stories with a global audience and thereby to build a stronger epilepsy community.

Developed in line with a strategy to advocate for appropriate legislation to guarantee human rights of people with epilepsy and to empower people with epilepsy to maximise their quality of life, International Epilepsy Day aims to highlight that:

- epilepsy still remains a hidden disease due to the stigma attached;
- it is treatable, yet 40% of people living with epilepsy in wealthier countries do not receive appropriate treatment. Over 70% of those living in low income countries cannot even access epilepsy medication regularly;
- lack of treatment imposes a huge financial burden on national health systems;
- research and legislation remain key issues in improving the quality of life of persons with epilepsy.

Around the world, IBE and ILAE associations are holding events to highlight issues of particular relevance at national or regional level, while, internationally a series of activities using the hashtag **#epilepsyday** will provide global outreach, uniting the voices of IBE and ILAE associations in the **more than 125 countries** in which the organisations are represented around the world:

- #epilepsyday on Facebook, Twitter and Instagram.
- #epilepsyday in photos: Around the world people with epilepsy will use smartphones to catch the mood of the day on #epilepsyday message cards in landmark locations. With membership stretching from New Zealand to the US, this will be a major activity!

epilepsy.org is a key repository for information on International Epilepsy Day.

In the European Parliament an exhibition tells the stories of people with epilepsy from around the world; official launch by Carlos Moedas, EU Commissioner for Research, Science and Innovation and hosted by Brian Hayes MEP, on 10 February.

Athanasios Covanis, IBE President, said "International Epilepsy Day is the opportunity to lend a global voice to people with epilepsy, a disease that can have devastating consequences, affecting all aspects of the lives of people with epilepsy. These are our most powerful advocates, and some of their stories, showing bravery in the face of advertisy, are showcased on epilepsy.org, demonstrating clearly that epilepsy is much more than seizures."

Emilio Perucca, ILAE President, added "International Epilepsy Day is a major step forward in raising awareness and improving the lives of people with epilepsy throughout the world. Its establishment is synergic with the approval, on 2 February, of the first WHO resolution on epilepsy by the WHO Executive Board in Geneva. The resolution, a true milestone, calls for a coordinated action in all member States to improve epilepsy care, protect the civil rights of people with epilepsy and increase investment into epilepsy research".

SERENE LOW

Malaysia

Talented Artist and Volunteer

As a young child Serene suffered from febrile seizures, caused by high fevers, but had outgrown these episodes by age 7. Then, during college holidays at a beach resort, she had a seizure while in the water and was rescued from near drowning. Tests confirmed generalized tonic-clonic seizures.

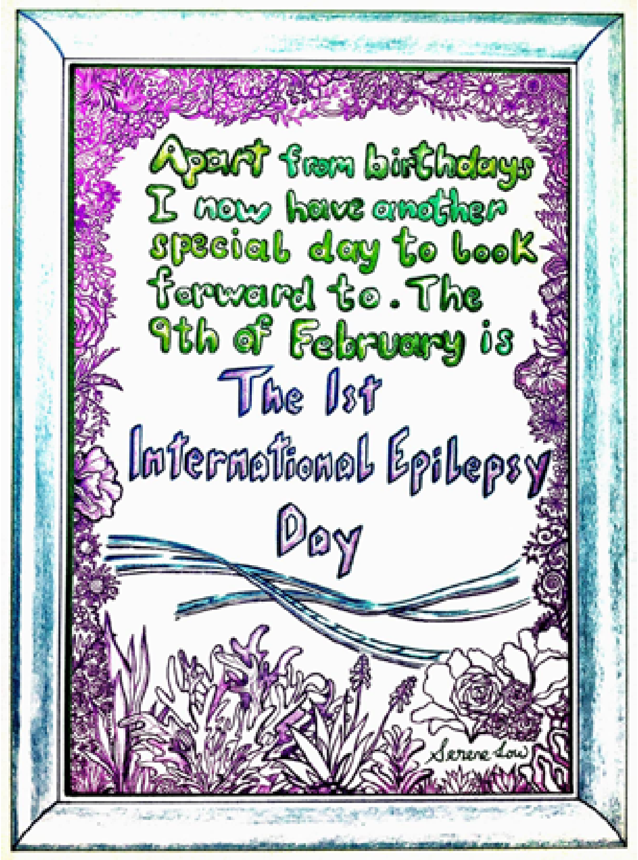
Her world had crumbled and she lost all sense of direction in life. She became withdrawn and had suicidal thoughts. She resented hospital appointments and threw away her medication, increasing seizure frequency.

Eventually Serene became tired of wasting her life. At age 19, her friends were at university and this made her bitter. But it was her fighting spirit that helped her change. Hospital trips became less daunting and medication was strictly adhered to. A better understanding of epilepsy was made possible by her neurologist and she learned to accept her condition as an illness that could be well controlled with proper treatment.

She has come a long way since, and has now lived with epilepsy for 36 years. A blog: "Serene's Epilepsy Legacy" was officially formed in 2002. In 2003, it was agreed that Malaysia Society of Epilepsy should form an epilepsy support group and she was appointed its coordinator.

In 2014, one of her fantastic paintings appeared in the book titled "Epilepsy - Perception, Imagination and Change." She is a self-taught artist and her art has been selected for exhibitions. She enjoys writing andis a passionate fundraiser and community worker for groups including National Kidney Foundation, Salvation Army, and World Wildlife Fund.

One philosophy that she holds dear is a quote from one of her poems: "Be joyful in hope and patient in suffering. Life with epilepsy is not without hope. Joyous hope comes about when we strive for positive change".



A small sample of Serene's artistic skills:
"Behind the Wall" (top right) and "Morphing" (below).
Serene created the picture above to celebrate the launch of International Epilepsy Day.

TONY COELHO
USA

Retired Democrat Congressman

Tony Coelho, who is of Portuguese ancestry, is a former United States Democrat congressman and the primary author and sponsor of the Americans with Disabilities Act.

Born in 1942, his first career choice was the priesthood. However, when he sent his application to join the Jesuit Order, a compulsrry medical exam showed that he had epilepsy, caused by an accident on his parents' farm when he was a teenager. Because canon law stated that a person with epilepsy could not join the priesthood, his application was rejected.

Even worse, once the diagnosis was then reported to the state, Coelho lost his driver's licence and his health insurance.

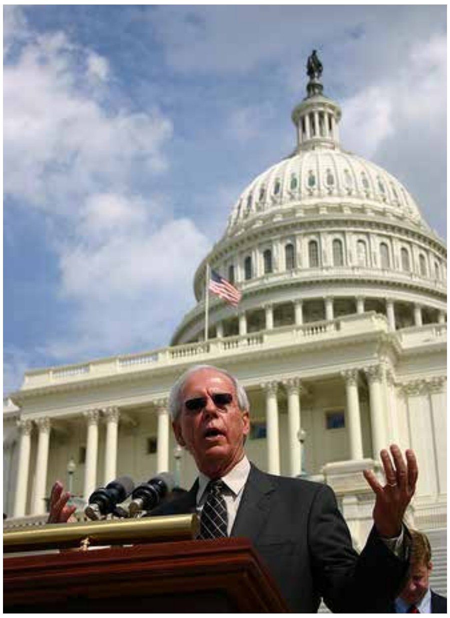
Still wishing to have a career of service, he then looked at the option of politics and in 1978 he was elected to the US House of Representatives where he went on to serve six terms. He retired from politics in May 1989.

Coelho now serves as Chairman of the America Association of People with Disabilities, the country's largest cross-disability membership organization. He was the original author of the Americans with Disabilities Act, signed into law by President George HW Bush.

President Bill Clinton appointed Tony Coelho to serve as Chairman of the President's Committee on Employment of People with Disabilities, a position he held from 1994 to 2001. He also served as Vice Chair of the National Task Force on Employment of Adults with Disabilities.

In 1998, he was appointed United States Commissioner General at the 1998 World Expo in Portugal.

He participates annually at New York Law School for its Tony Coelho Lecture in Disability Employment Law & Policy. He also serves on the National Board of Directors of Epilepsy Foundation of America and remains a terrific supporter and advocate for people with epilepsy.



Join Us on Social Media and Post Your Pic!

Social media is playing a major role worldwide in celebrating International Epilepsy Day. Already, thousands of people are following us on Facebook and Twitter is also really busy.

On February 9th there will be a worldwide effort to get **#epilepsyday** to trend on Twitter and other social media sites. We're looking for all social media users to post a photo on the day using a sheet of paper to display the hashtag and your location. If you don't use social media, you can send us your photos and we will post them for you!

Be part of the worldwide social media effort:

- Change your cover photo and profile picture to the International Epilepsy Day logo available on the download page of epilepsy.org
- Share content and promote International Epilepsy Day using the hashtag #epilepsyday
- Take a "selfie" in a famous location in your country with the #epilepsyday card.

Let's seize the day for epilepsy1.

#epilepsyday at WHO, Geneva

Taking the opportunity to play a part in the International Epilepsy Day photo event, while attending the WHO Executive Board Meeting in Geneva, Switzerland are, from left to right:Tarun Dua, Programme for Neurological Diseases and Neuroscience, Department of Mental Health and Substance Abuse, WHO; Mary Secco (Canada), Co-Chair IBE-ILAE Global Outreach Task Force; Shihuo Li (China), Member IBE-ILAE Global Outreach Task Force; Emilio Perucca (Italy), ILAE President; Athanasios Covanis (Greece), IBE President; Alla Guekht (Russian Federation), Co-Chair, IBE-ILAE Global Outreach Task Force; and Ann Little (Ireland), IBE Executive Director.

EMILIA SALMINEN
Finland

Emilia's mother thanks epilepsy surgery

Five-year-old Emilia Salminen, from Finland, underwent extensive frontal-lobe surgery in the spring of 2014. Emilia's operation was performed at a hospital in Helsinki. She was in surgery for eight hours.

Emilia's epileptic seizures were caused by a congenital developmental disorder of the frontal lobe. When the condition was at its worst, she suffered dozens of episodes a day. Medications did not seem to help. After numerous and exacting examinations, epilepsy surgery was decided upon. Although Emilia no longer suffers from seizures, she continues to take epilepsy medication and her progress is carefully monitored.

The results of the operation have already surprised her parents and grandparents. Her epileptic seizures have stopped, and she has become more outgoing and self-confident. Her frequent nightmares are gone, and her daily life is easier.

Emilia now goes to a specialised day-care facility, and her mother can rest assured that she is receiving the best possible care and support from the expert, friendly personnel. Emilia has joined a swimming group. The aim is, of course, to learn how to swim on her own. Emilia has also started skating and finds it an enjoyable hobby.

Emilia´s mother Tiina and Emilia have also taken part in an adaptation family training course organised by Finnish Epilepsy Association. The best things about the course were peer support and learning how to approach and cope with epilepsy issues. Tiina is quick to emphasize the importance of her own attitude. With this positive attitude Emilia´s family can now look to the future of their lovely child.

SUPERSTITION CAUSES DISCRIMINATION

Hermes is 29 years old and lives in Blantyre, Malawi. He is the sixth born of a seven-children family. He has a wife, Ruth, and a young son.

He suffers from convulsions and also has absence seizures. He has never seen a neurologist: his medical assessment and medication were provided by a nurse.

"Due to my epilepsy I have been a victim of discrimination and inhuman and degrading treatment, to the extent that I was denied opportunities such as socializing with friends and participating in developmental activities", says Hermes.

He belongs to a chiefdom and could have inherited the throne from his uncle, who was a chief, when he died 8 years ago. However, the elders have put a caretaker chief in place while they consider the situation. In their opinion putting a person with epilepsy on the throne would be against their ancestors will and would invite the wrath of the community.

Hermes has had employment problems, despite obtaining a diploma in Rural Community Development. No company or individual has beenwilling to offer him a job, despite many efforts. Finally, he became involved with the FEDOMA Epilepsy project, which he joined as a volunteer and started seeing a brighter future on the horizon.

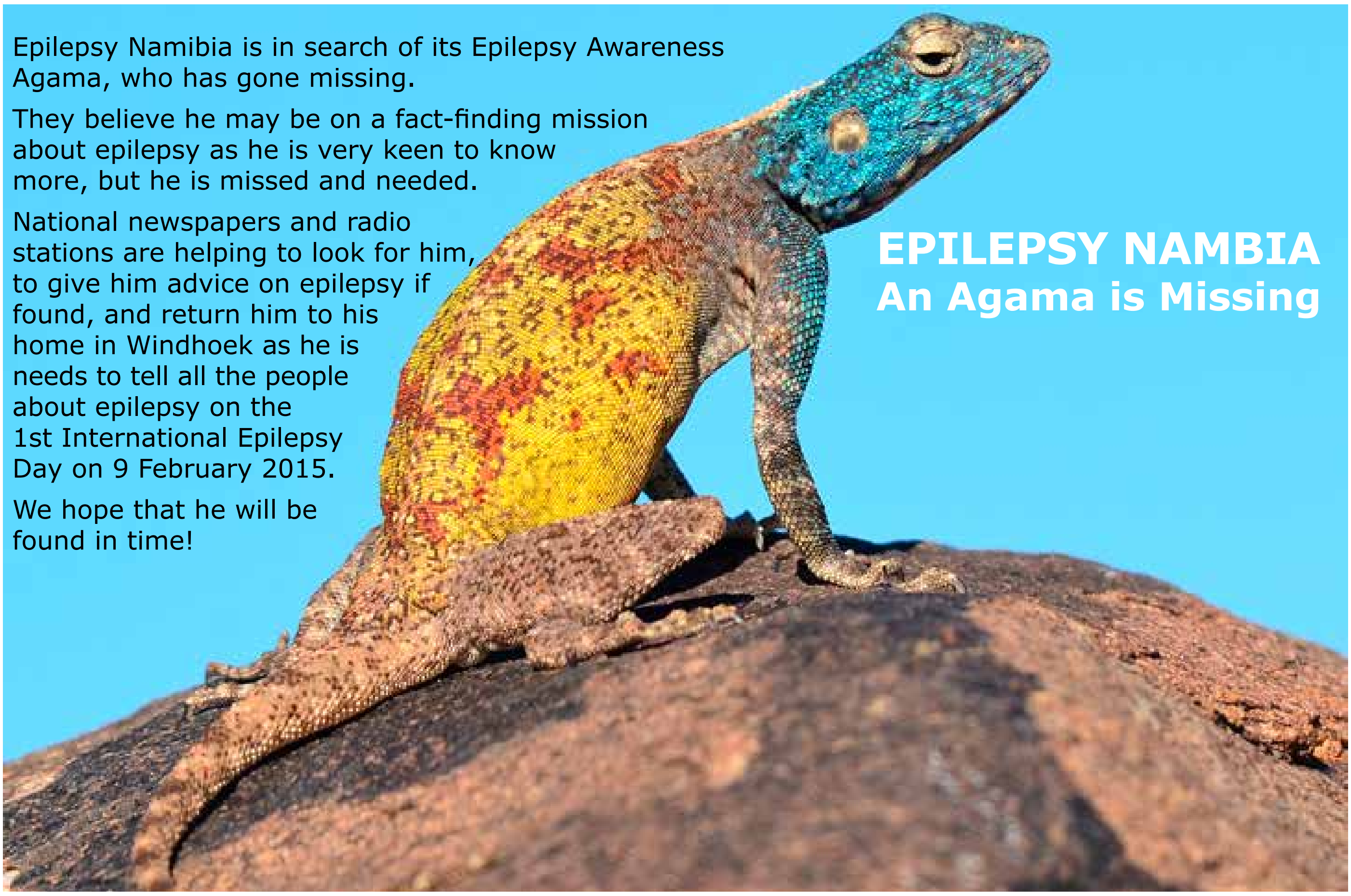
Hermes tells that, during his school years he has faced a lot of problems. He missed many days of school because of his disability, and there was no specialist teacher to help him.

Herman likes to play soccer, listens to music and composes songs. He also likes poetry and writes poems. He keeps himself informed on current affairs by watching TV, listening to the radio and reading newspapers.

HERMES TEBULA
Malawi

Around the World
on International Epilepsy Day

In every corner of the world, IBE and ILAE associations are planning a wide range of activities to celebrate International Epilepsy Day. Events range from awareness campaigns, media events and special videos, to fundraising dinners and concerts. Here is just a very tiny sample of What's On.



EPILEPSY NAMBIA
An Agama is Missing

Epilepsy Namibia is in search of its Epilepsy Awareness Agama, who has gone missing.

They believe he may be on a fact-finding mission about epilepsy as he is very keen to know more, but he is missed and needed.

National newspapers and radio stations are helping to look for him, to give him advice on epilepsy if found, and return him to his home in Windhoek as he is needs to tell all the people about epilepsy on the 1st International Epilepsy Day on 9 February 2015.

We hope that he will be found in time!

MONGOLIA

Raising awareness and understanding will be the key targets in Mongolia to mark the first International Epilepsy Day.

Across 21 provinces and in three different cities, family doctors, specialist consultants, people with epilepsy and their families are being invited to attend special seminars on epilepsy.

The first International Epilepsy Day will also be promoted to the public at large through media events and placement of posters in public spaces.

EPILEPSY IRELAND

Epilepsy & Sport

Ireland Rugby head coach, Joe Schmidt (seen here with his #epilepsyday message), features on an advertising campaign highlighting seizure first-aid. Originally from New Zealand, Joe has a son who has epilepsy and is a major supporter to the Irish association.

We all know the health benefits of taking part in sports and physical activities, but Epilepsy Ireland plans to find out more about the relationship that people with epilepsy in Ireland have with sports and exercise.

BRAZIL

The Brazilian Association of Epilepsy (ABE) is holding a major event in São Paulo to mark International Epilepsy Day.

Bringing together people with epilepsy and their families, health and educational professionals, students and the general public, the objective of the event is to fight for rights to economic, professional and social inclusion of people with intractable epilepsy.

The aim is to reduce the discrimination and exclusionary attitudes to which people with epilepsy, in particular intractable epilepsy, are often exposed.

The event will be held at the Legislative Assembly of São Paulo.

INDONESIA

Epilepsy Unmasked

To mark International Epilepsy Day, Yayasan Epilepsi Indonesia is holding a media event to encourage media reporting of the day.

Using the theme 'Unmask Epilepsy' the press event will welcome journalists from newspapers, TV, radio and online reporting.

With guess speakers Dr Fitri Octaviana Sumantri and Dr Irawan Mangunatmadja, the event takes place in the Double Tree Hotel.

Love is the answer: love of my sons and my grandchildren

HELIA VALENZUELA
Chile

Helia is now 59 years old and has had absence epilepsy since she was 15 months old. Her classmates never made fun of her and she loved school. When she left school, her ambition was to study dentistry, but in the end, she joined the Chilean Naval Army as a telegraph operator, proudly graduating from training with honors, despite her epilepsy.

But not all was perfect: a few months later, Helia had a major seizure, which resulted in discharge from the Navy. It was the first time that she was angry about her epilepsy. She asked herself "Why me?"

She had to begin building her life again from zero and decided to study for a secretarial degree. A few months later, she met her future husband and they had three children. She felt fulfilled. But her happiness was short-lived. Her husband deserted her and she was left with sole responsibility for both children and home.

But worse was to come. At the age of 35 years, she developed a tremble in her voice and hands and her condition then deteriorated to the point of not being able to talk, eat or take a shower without help.

She became dependent on others and experienced depression. However, after years of rehabilitation, she learned to take care of herself and decided that epilepsy was not so bad – there were worse things in life. How right she was: a cerebral aneurysm meant urgent surgery and pulmonary bleeding after the operation left her in a coma for 8 days. But she survived.

'If people ask me where I manage to find strength to overcome everything that has happened, I tell them that love is the answer. Love of my sons and of my grandchildren, love of all the wonderful - and not so wonderful - things in my life', says Helia. 'My experiences have helped me realise that I was born a fighter and I will die fighting the battle', she adds.

SHENAZ HAVELIWALA - India

Volunteer and Entrepreneur

Epilepsy has changed me as a person. It has taught me more than any university possibly could.

Shenaz was 19 and a mechanical engineering student when she had her first seizure. She had to leave university as her seizures did not respond to medication. Two years later she took the very brave step to undergo temporal lobe surgery.

During recuperation, Shenaz met patients from different cultures, financial backgrounds and age groups, each with a story to tell. She realized that everyone had his own problem; epilepsy just happened to be hers. This was the catalyst that has le to an incredible amount of volunteering work.

In 2009, Shenaz collected funds through social networking websites, which she donated to the hospital where her surgery had taken place. The fund covers treatment cost of patients who otherwise would not be able to afford it.

In 2010, she started volunteering at the Indian Epilepsy Association, teaching members English, basic math and logic. She organizes sales events in Mumbai where members display and sell their handmade products. This helps them financially as well as giving employment. Independently, she interacts with Indian media to highlight the true facts about epilepsy – an invisible disease –and speaks about her life with epilepsy at seminars.

Her seizures continue to occur and she struggles to overcome side effects of current medication. But, she's happy to visualize the world her way. In 2011, despite uncontrolled seizures, she turned entrepreneur, transforming her father's warehouse in Mumbai into a rent-by-day workspace called 'SoboConnect'. She now finances her own medical expenses. This is when she graduated, earning a website designing certificate, despite of having 60 seizures that year.

She has stopped pondering the 'why' in life and now focuses on the 'how'.

Currently, along with her Master's degree, she volunteers with ADAPT (formerly the Spastics Society of India), as an assistant special educator.

In 2014, IBE awarded her as an Outstanding Person with Epilepsy at the Asian & Oceanian Epilepsy Congress in Singapore.

'Epilepsy has changed me as a person', she says, 'it has taught me more than any university possibly could.'

SANDRA VALDEBENITO

Chile

What does not kill you makes you stronger!

Sandra is now 41 years old. There is a family history of epilepsy: her uncle also had the disease but the family didn't see this as normal. She often saw her grandmother and mother crying, because her uncle was financially and physically dependent.

When she was 17 years old, she had an episode that would mark her life forever. The only thing she remembers is waking up and hearing her parents crying on their way to the hospital. After a battery of tests and neurologist appointments, the diagnosis came: Juvenile Myoclonic Epilepsy.

She thought about her uncle and was afraid, she didn't want to have the same experiences.

While her mother begin overprotecting her, Sandra decided epilepsy was not going to dictate her life. A year later she became pregnant. She was afraid and she stopped taking her medication. She miscarried.

After school, Sandra married and, a few years later, Israel was born. This time she sought professional help and had a healthy baby. Now she had a husband and son: proof that she could have a normal life.

Seven years later, she had a baby girl. Born at 30 weeks, Martina was diagnosed with Pierre Robin syndrome, arthrogryposis, and with muscular and osseous atrophy in her arms. She spent the first 11 months in hospital and had 30 life threatening episodes. Today, Martina is a beautiful 12 year old.

But, life had another surprise: at 15 years Israel fell down. Sandra knew straight away that he too had epilepsy. Now, all her talk of independent living seemed rubbish. She just wanted to hold him close and not let him go. She realized why her parents had acted as they had done and, even now, she has to resist being overprotective of her son.

Today, Israel is employed and has plans for his future. Sandra is studying First Aid, is working and feels strong.

'What does not kill you, makes you stronger,' she says.

ALFIE SCOTT
UK

A special boy who loves a cuddle

Alfie is 8 and lives with mum, dad and two cats. He goes to a specialist school for children with visual and other disabilities and was pupil of the year last year. He loves a cuddle, swimming, chocolate, and going in his wheelchair on bumpy surfaces, or in the wind and rain, which can make him laugh.

Alfie was found to have multiple brain malformations when he was 2 days old, had his first seizure when at the age of 3 months, and has never been free of attack since.

He is one of over 60,000 children in Europe with an epileptic encephalopathy. These are a group of conditions characterized by childhood onset frequent seizures, which don't respond to standard drugs, together with developmental delay, severe cognitive and sometimes behavioural problems.

By the time he was 5, Alfie had tried 7 different antiepileptic drugs as well as the Ketogenic diet, with limited success, and had multiple hospital admissions with chest infections. It is the unpredictable nature of his epilepsy and sleepiness that his parents find hardest to live with, and which most affects his quality of life.

Physical disabilities can be compensated for with equipment and extra help, but if he is having lots of seizures or is unresponsive, you just have to wait for the bad spell to pass - which can last hours, days or even weeks. Other days he can be very bright and smiley, lifting the mood of people around him as well. His epilepsy is about much more than seizures.

Alfie's parents' main aspiration is that they can continue to support Alfie to have the best life he can. Improved awareness and understanding about epilepsy and disability underpin this, as well as investment into services and support for such children and their families.

Research is also starting to unlock some of the mechanisms and lead to new treatments. This of itself provides hope, the importance of which, in challenging circumstances, cannot be underestimated.

You can choose to look beyond your circumstances and rejoice, or allow yourself to be overwhelmed with self-pity

MING YING GOI

Singapore

I grew up seeing my parents struggle to make ends meet and told myself I had to study hard. I was an above average student and good at sport, representing my school in competitions.

In June 1989, during training, I had a fall that resulted in a brain injury. It took a year before I was diagnosed with complex partial epilepsy. I had to stop running competitively because tiredness would bring on seizures.

Hospital became like a second home. I became depressed but with the encouragement of family and close friends I learned to accept my illness.

Friends were afraid whenever I have a seizure. They did not know how to manage and slowly my circle of friends dwindled. To help myself, I began to read up about epilepsy and how others could help me when I had a seizure.

Slowly I started running leisurely again and playing badminton with my friends occasionally.

Finding employment was a concern but I started as a programmer and slowly moved up the ranks. But stress and long hours increased the frequency of my attacks. I resigned and found a job as an IT project manager.

Work remains stressful and I do have occasional seizures but understanding supervisors and colleagues look out for me. My memory deteriorated after years of having epilepsy so I always write down tasks assigned to me. To compensate for the times that I am unwell, I work doubly hard when I am well.

I also have hypertension and multiple failed knee surgeries means I need to use a stick or wheelchair. Chronic pain has become part of my life. I am a member of Epilepsy Care Group Singapore, who supported me during my darkest moments. You can either choose to look beyond your circumstances and rejoice, or allow yourself to be overwhelmed with self-pity. I have chosen the former.

ROB WIERZBICKI - Australia

Dedicated Volunteer

In 2014, Rob Wierzbicki was Australian recipient of the Outstanding Person with Epilepsy Award, honouring his volunteer service to the Epilepsy Foundation of Victoria, spanning 16 years. He was presented with the award at the 10th Asian & Oceanian Epilepsy Congress, Singapore.

Rob was introduced to the Foundation when he was diagnosed with epilepsy at the age of 22. He obtained as much information as he could about epilepsy so he could learn, as he says, "about this medical condition that was to affect for the rest of my life".

Rob's epilepsy is now under control but, since 1995, he has been one of the Foundation's greatest volunteers, as a trained community speaker and a regular camp volunteer. He began his involvement with AWEsome (Adults with Epilepsy) group in 1997. The group aims to give young people and adults the confidence to be socially active while living with epilepsy.

In 2003 Rob and his wife Cheryl were asked to become the volunteer co-ordinators of the AWEsome group, which they willingly took on, at the same time as having very small children! Rob and Cheryl now have three children – Riley aged 8, Jordon aged 7 and Tahlia aged 5.

Rob juggles full time work with National Australia Bank, where he has been employed for the past 25 years, with a full family life and his service to the Foundation. He sees his volunteer role as a way of giving back and making a difference to people who live with epilepsy.

"I still love being involved with the group. Even though I have three young kids to keep me busy, I get so many rewards from the AWEsome activities and camps".

Rob continues to be on the leadership committee with the AWEsome group, and values every opportunity to see so many of the participants flourish and grow in confidence.

Rob sees his volunteer role as a way of giving back and making a difference to people who live with epilepsy

FUTURE CONGRESSES

3rd East Mediterranean Epilepsy Congress

Amman 2015

31st International Epilepsy Congress

ISTANBUL 2015

www.epilepsycongress.org