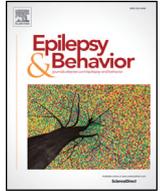




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From the International Bureau for Epilepsy

IBE Golden Lights Awards reward triumph over adversity



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, and friends.

The Golden Light Award honors 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, the awards have been presented at each Asian Oceanian Epilepsy Congress since then. The Asian Oceanian Epilepsy Congress is organized biennially jointly by the International Bureau for Epilepsy (IBE) and the International League Against Epilepsy.

The award recognizes 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.

The International Bureau for Epilepsy now plans to roll out the awards in each region. In the future, they will be presented at the other epilepsy congresses in which IBE is a partner in the African, Caribbean, Eastern Mediterranean, and Latin American regions.

The awards were presented most recently at the 12th Asian & Oceanian Epilepsy Congress, which took place in Bali in May

2018. The photograph shows IBE President Martin Brodie with the three awardees – Katherine Height, Shurong Huang and Ern-Chun Hung – to his left. Here are their personal stories:



Shurong Huang, China:

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 would not 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 did not 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 were 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 is 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 nonprofit online platform called “Eclampsia Home”. It is an online shop that helps people with epilepsy to sell homemade 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 is even brighter than one can imagine.

Katherine Height:

My name is Katherine Height; I am 25 years old and live in a regional town in South Australia called Mount Gambier.

In 2009, my whole world changed when I learnt that I was going to be a Mum at the age of 17 years. On January 25, 2010 at 09:45 my beautiful baby girl, Ella Grace Gray, was welcomed into the world. With big blue eyes and a gorgeous dimple in her cheek, she was perfect.

At three months of age, Ella experienced what we believe to be her first seizure; she went limp, blue around her mouth and stared. We rushed to our local GP, an ambulance was called, and we were taken to the hospital. Ella was admitted to the pediatric ward for three days and discharged with a diagnosis of febrile convulsion due to a viral infection.

Over the next 11 months, Ella grew, hit her milestones, and we could see her bright funny little personality coming through. We

experienced more of those random events with Ella staring and hospital trips, but it all came back to viral infections. But in November 2012, Ella experienced her first tonic-clonic seizure. Ella stood still and then fell backwards, her whole body stiffening and jerking uncontrollably. I remember so vividly the image of my little girl, her whole body being taken over by the seizure, the sounds of it all. I called for an ambulance, and we were taken to the hospital. The emergency doctor said Ella had a viral infection; however, the pediatrician also came in and said he was going to do a referral to a neurologist in Adelaide.

Three months later it happened again, two days before we were due to see the neurologist. This time Ella had six seizures within 24 h. We were initially on the pediatric ward but then moved to the high dependency unit, and Ella was given a loading dose of medication to stop the seizures and allow her body to recover. That day my world changed; the pediatrician came to us and said that it was clear our daughter had a seizure disorder. Ella started on her first antiepileptic medication.

Ella’s seizures then changed, and she was experiencing primarily absence/focal seizures; I believe more than 30 a day. She had two electroencephalograms (EEGs), two magnetic resonance imaging (MRI) scans, and a positron emission tomography (PET) scan, all under general anesthetic; trialed six different medications with different combinations all over the space of three years until we finally got a video-EEG (VEEG) scan that showed what I had been witnessing.

In July of 2015, our neurologist suggested we consider genetic testing. Three months later, we got the answer. Ella had a mutation of the *SLCA2A1* gene – Glut 1 deficiency – a rare genetic disorder for which there is currently no cure.

Within two weeks, we began the ketogenic diet, with which I have developed a love/hate relationship. Initially, it was such a huge learning, and I remember thinking “how am I going to do this?” It has been almost three years since Ella began the diet. It gave us a period of 8 weeks seizure-free in the beginning, but sadly, that has not continued, and Ella is still currently experiencing more than 80 seizures a day. However, the diet lifted “the fog”, and her concentration and cognitive levels improved dramatically, which had a huge positive impact for her at school.

As well as the diet, Ella is on a combination of three antiepileptic medications. We also regularly see an occupational therapist and physiotherapist for Ella’s ataxia, mild developmental delay, and motor planning issues.

Ella’s condition has given me a passion I never knew I had. As well as fighting for a diagnosis for Ella, I am also fighting for change and equality. South Australia still does not recognize epilepsy as a disability, which would provide government funding and support.

I created Ella’s Purple Promise, a local fundraising initiative with a motto to celebrate, educate, and advocate for epilepsy awareness. All funds raised go to The Epilepsy Centre based in Adelaide. I have also featured in different media outlets including, national magazines and radio, as well as articles within our local newspaper, sharing our story and creating awareness.

Through all of this, the shining light that keeps me going and is my inspiration is my beautiful daughter Ella. I could not be prouder of the way she has handled all that has been thrown her way; she rarely complains, she tries her absolute best and lights up a room with her bright personality and gorgeous smile.

I am not a professor; I do not have a degree; I have not made it to university yet. I am a Mum. A Mum on a mission to continue to celebrate, educate, and advocate for epilepsy, to see a change in the world, a change in how this condition is preserved and accepted, to be here when new things are discovered, treatments, medications, and the ultimate hope, a cure.

None of this would have been possible without the truly incredible support network I have in family and close friends.

To finish I would like to share a quote that, to me, fits our journey, keeps me going, and is something I am extremely proud of.

“I didn't give Ella the gift of life, Life gave me the gift of Ella.”

Ern-Chun Hung, Taiwan:

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 skill.

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. During the weekend, I spend a lot of time with my loyal friends, playing piano and singing. Life treats me 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, the love and the attitude I have for life – a positive and love-yourself attitude. Epilepsy is no longer an obstacle; it is a jumping stone to a journey of self-discovery.

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