



IBE FOCUS ON YOUTH

The TEA Room

Young Adult Summit

Golden Light Awards

?

My Story

Leadership Training Programme



EpilepsyNext

IBE focus on youth

Building confidence, recognising ability and supporting capacity in young people, both at national and international level, is an important element of the work of IBE. This is highlighted as one of our aspirations in the Strategic Plan from 2016-2019. Our goal is to improve unity, sustainability and communication, not only among IBE members, but also with IBE's 138 chapters in 104 countries around the world.

The development of EpilepsyNext, a wide-ranging youth platform, will represent a major element of our work programme over the coming four years and beyond. EpilepsyNext is an exciting development that sets out to help young people grow in independence and develop the skills and qualities necessary to have a happy and productive life and, for some, to learn how to be effective leaders. It also challenges them to use these attributes for the betterment of themselves and the global epilepsy family.

The project currently consists of five programme modules. In time we expect to introduce further components. Each can be used by the young adult as a stand-alone element. In addition, some young adults may decide to explore a number of modules as they grow in confidence and ability.

AIMS AND OUTCOMES

The EpilepsyNext platform aims to:

- Enable young people to grow in confidence and to recognise their unique talents and abilities
- Support capacity in young adults to make a difference in society through the development of communication and leadership skills

5 MODULES

1. The TEA Room
2. Young Adult Summit
3. Leadership Training Programme
4. Golden Light Awards
5. My Story

The TEA Room

TheTea-Room.com (<http://www.the-tearoom.org.uk>)



THE TEA ROOM
A Friendly Space for Young People with Epilepsy

Home About Us Being a member My Page For Parents Your Stories

The Tea Room for Young People with Epilepsy

Welcome to The TEA Room. We are a friendly space for teenagers with epilepsy.

Keep it Friendly

Friendly Community :)

Please report any and all abuse of this website to info@thetea-room.com

For internet safety information please click on our Information for Parents link above.

Or visit www.thinkuknow.co.uk

CLICK CEOP
Child Exploitation and Online Protection Centre

Follow The TEA Room

Chat online with other teens with epilepsy

The teenage years can be a traumatic and challenging time for many young people. Peer pressure, the wish to be the same and yet different, changing hormones and developing bodies can all exert emotional influences. For young people with epilepsy, the desire to be the same as their peers, to be able to stay out late and party until dawn,

to drink alcohol, to go on dates, to enjoy nightclubs with flashing lights, can bring extra stress.

The TEA Room (Teenage Epilepsy Agenda) recognises the value of peer support at this challenging time in young people's lives. Already well-developed and successful, this project represents a safe online environment for teenagers with epilepsy to meet and discuss issues of relevance to them – not only those that might relate to epilepsy, but also their day to day activities and interests. The TEA Room is managed and moderated by Scottish Epilepsy Initiative, a registered charity based in Glasgow, Scotland (Scottish Charity Number SC034354).

The project was initiated in 2011 and expanded to Australia in 2012. Now the TEA Room has grown to be a worldwide site available to anyone, anywhere, aged between 13 and 19 years. Communicating with peers in a safe and comfortable environment is the ideal starting point to build confidence in young people allowing them to speak freely without fear of discrimination about how it is to live with a diagnosis of epilepsy. Discussions, among its many users, however, include a wide range of topics from sitting a driving test to going to a concert.

More than 500 people are currently accessing the website from 15 different countries. Our plan is to extend its remit by raising money to provide education and training opportunities for some of the young users of the platform across the world. This includes funding for schooling, college and university fees, developing sporting expertise and support for training opportunities and apprenticeships.

Budget

A global fundraising programme will be developed by our Finance Committee to underwrite this project. All moneys raised in a country or region will be spent there in supporting the education and training of young people with epilepsy.

Leadership Training Programme



IBE recognises the need to identify and equip its next generation of leaders, if our organization and chapters are to develop and expand to meet the changing environment of an increasingly complex world. The voices of people with epilepsy are crucial to any discussion concerning aspects of their everyday lives.

The IBE Leadership Training Programme represents an exciting opportunity offering tailored high-quality support to young people (18-30 years), who have the motivation to learn more about advocacy and to maximise their leadership potential.

The programme will be divided into separate learning modules and will equip young people to:

- identify the strengths and motivations that inspire them to become leaders
- develop a clear vision of what they would like to achieve as a leader
- explore the challenges of leadership and develop their personal style
- apply methods of conflict resolution by developing clear communication skills
- practice problem solving and critical thinking as part of an interactive group
- learn how to initiate change to better fight discrimination and stigma
- look past themselves at their community and the wider epilepsy society

It is envisaged that the leadership training programme will be provided through a range of themed workshops with a limited number of participants. Some will run as stand-alone events, while others will take place during congresses. Training will be provided by experienced professionals working in the epilepsy field.

Criteria for participation will include being within the age bracket of 18 to 30 years and submitting an application form and letter of recommendation from a national IBE association. Bursaries will be provided to assist with travel and accommodation costs. The first training course will take place during 2018 with a maximum of 30 participants.

Budget for first training workshop: €27,500

Travel: €9,000 Accommodation: €9,000 Training materials: €3,000 Venue: €3,000 Administration: €3,500

Young Adult Summit

An event organized by the IBE North American Regional Committee in 2014, gathered 20 young adults from Canada, Jamaica, Puerto Rica and the USA. This led to the development of a media project that already has generated compelling videos highlighting the personal stories of triumph over diversity in young adults with epilepsy.

The summit

- provided a forum for the young adults to network with each other to share their personal stories about epilepsy, both as medical and social conditions
- identified the gaps and challenges that had prevented other young adults living with epilepsy from participating as fully as possible in their community
- developed a project that the group has since set up to improve the lives of other young adults living with epilepsy



Two years later, its success, which led to the reMARKable videos, is evident in the continued active engagement of the young people in the project. IBE would like to further develop this programme in each IBE region.

It is expected that some summits will take place at the time of the regional congresses with IBE regional committees and national chapters being invited to play an active role in promoting the programme to young adults with epilepsy at a national level. Social media will also be used to attract interested young adults. The first summits could take place at the 12th Asian Oceanian Epilepsy Congress in June 2018 in Bali, Indonesia and the 10th Latin American Epilepsy Congress in September 2018 in San Jose, Costa Rica. The plan also includes a stand-alone summit in Europe.

The programme content used for the North America Young Adults Summit has already proven to be a successful model, which can be adapted for use in other regions. Targeting a general audience aged 30 years and younger, as well as people affected by epilepsy (patients, family, friends, work colleagues), the objectives of the campaign will be:

- to educate through inspiration
- to show that epilepsy is not a barrier to success
- to give an accurate representation of epilepsy
- to educate society and to end stigma
- to empower people to feel comfortable talking about their epilepsy

The Young Adult Summit differs from the Leadership Training Program in that it provides a dedicated forum for exchange and personal development for those aged between 19 and 30 years who do not have an interest in developing leadership skills.

Budget for three summits (30 participants at each): €90,000

Budget figure includes travel, accommodation and catering, meeting materials and administration

GOLDEN LIGHT AWARDS



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, the awards have been presented at each Asian Oceanian Epilepsy Congress since then. Now we plan to roll them out at the other regional epilepsy congresses, in which IBE is a partner in the African, Eastern Mediterranean and Latin American regions.

The awards recognise 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'.

CANDIDATES

Candidates must be under the age of 35 years in the year in which the award is presented and must submit a short, written article telling their story about living with epilepsy. Those with the three best submissions will be invited to present their story during the Epilepsy and Society Symposium, that will take place during the relevant congress. They are also posted on social media and on the IBE website to highlight success in the face of adversity.

All candidates selected for a Golden Light Award will be presented with a trophy and scroll during the opening ceremony at the congress.

NOMINATIONS

Each IBE chapter in the region in which the congress is taking place may nominate one recipient for the award bearing the following in mind:

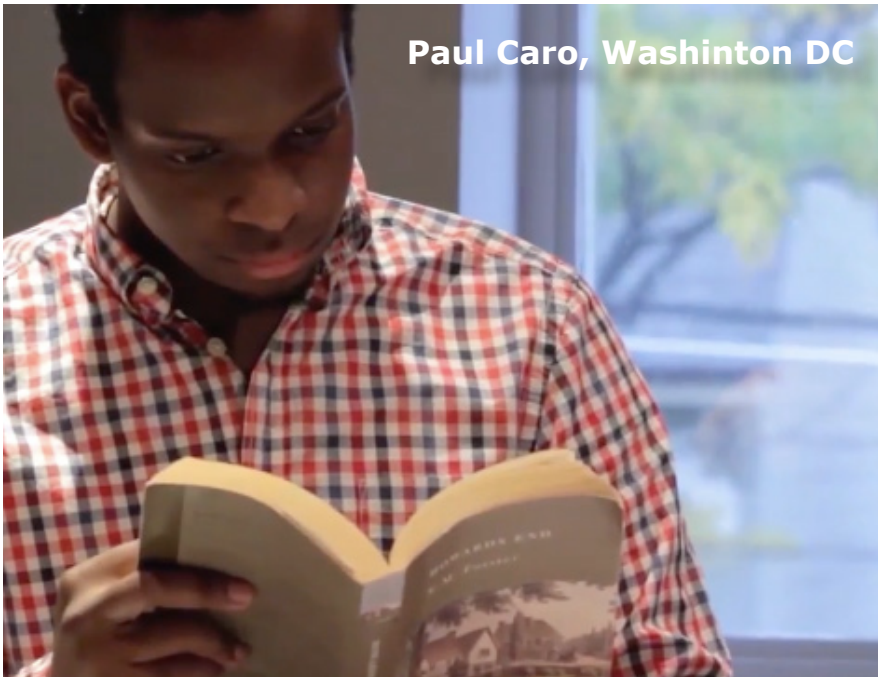
- Contribution to community service
- Support for people living with epilepsy
- Individual achievement (personal, professional, educational, sporting, creative)
- Advocacy for epilepsy (community, political, media)
- Distinguished service to a local epilepsy support organisation

PRIZE ENTITLEMENTS

In addition to the trophy and scroll, each candidate will receive support for travel to the congress in which the award is being presented, hotel accommodation, and free registration to the Epilepsy and Society Symposium.

Budget for first year (awards at two congresses): €25,875

Travel: €7,000 Accommodation: €6,000 Symposium: €7,500 Awards: €2,000 Administration: €3,375



Paul Caro, Washinton DC

MY STORY

Effective stories inspire people by creating human connection and emotional resonance. Good narratives move hearts and minds and can lead to meaningful action. We all recog-

nise that percentages and numbers don't mean anything until you see them through the lens of a human life. This is what made the reMARKable videos that were developed from the North American Young Adult Summit such a success. View them at epilepsy.org.

How a story is told is just as important as the story itself. Many people have powerful and positive personal narratives that can inspire and inform about living with epilepsy. Now we would like to support them in sharing their story in their own voice without stereotyping or victimising. Their stories will let us, and the world, know that a person is more than their illness.

To do so, we plan on holding the first communications workshop in Europe in 2018. The workshop will provide guidance and advise on how best to tell a story with tips on holding audience attention – whether that be online, through social media or live. We would then hope to roll out other workshops around the world.

The workshop will take the form of an interactive session providing tips and tools for communication with external stakeholders, learning how to develop and script a media story and how to work with media from live presentations and media interviews to video recording. In addition, over time, IBE will build its own repository of stories and story tellers that will form a powerful testimony to inform the public, teachers, healthcare providers and policy makers as well as other people living with epilepsy.

If information coming at you doesn't get through your heart, it won't make it to your head.

Andy Goodman

Budget for first workshop (30 participants): €30,000

Travel: €9,000 Accommodation: €9,000 Training materials: €5,000 Venue: €3,000 Administration: €4,000