



IBE FOCUS ON YOUTH 2020 EDITION

Supporting capacity in young adults through the development of communication and leadership skills



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 2019-2023. 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, represents a major element of our work programme over the coming years. 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 consists of a number of modules. Each module 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 Epilepsy Next 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

4 MODULES

1. YEAH (Young Epilepsy Advocates Hub)
2. Young Adult Summit
3. Golden Light Awards
4. Youth Council



Moving from childhood to adulthood 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.

YEAH (Young Epilepsy Advocates Hub) recognises the value of peer support at this challenging time in young people's lives. This project represents a safe online environment for young people 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 upper age limit is 30 years.

YEAH replaces the TEA Room, an initiative set up as an online forum for those in their teenage years by the Scottish Epilepsy Initiative (SEI) and which SEI has kindly provided to IBE. Reflecting changing times and advances in technology since the TEA Room was created, YEAH now operate through Facebook. The Facebook page is in place (<https://www.facebook.com/YEAHepilepsy/>) and the group page, for member discussions (<https://www.facebook.com/groups/YEAHepilepsy/>) has also been created. Both are now live.

Meanwhile, the TEA Room Forum will remain open for a few months to facilitate those transferring from the old platform. Thereafter, visitors to the TEA Room Forum will be automatically redirected to the YEAH Facebook page.

Active promotion of the YEAH module is already happening through a Press Release, posts on other IBE social media accounts and eZines. We are also making contact with some of the Golden Light awardees to invite them to get involved with the option to assist with moderating the group page of this initiative.

And young people are already engaging!

Young Adult Summits

There is wide recognition amongst IBE's chapters that young people are currently under-represented in their associations. This poses the risk of undermining the future potential of epilepsy associations or, at worst, putting their very future in jeopardy. It is also felt that the issues facing young people affected by epilepsy are not getting the public or political attention they should. Yet the diverse range of experience and the remarkable personal resilience that a large number of young people with epilepsy already demonstrate is going unnoticed, because many feel ill-equipped to report on their achievements.

Recognising this and in line with IBE's goal 'to provide resources for people with epilepsy and their families to maximise quality of life', IBE is developing summit workshops especially for young adults with epilepsy either as stand-alone events or at the time of regional or international congresses. The objectives of these summits is:

- To offer a platform for young people to voice the issues they face and raise awareness of these issues;
- To provide young adults with epilepsy with the skills to become epilepsy advocates, in partnership with IBE's chapters in Europe;
- To hear how young people with epilepsy perceive patient organisations and how IBE, together with its chapters, can better adapt its operations to embrace the views and expectations of these young people with epilepsy;
- To harness the outcomes of the workshop towards building a political campaign that could be brought to national policy makers;
- To encourage participants to channel their results into a project that will address one of more of the issues that they believe should be addressed in order to improve life quality for those affected by epilepsy.

The ultimate aim is their involvement in developing IBE's Youth Council.

In 2018, a very successful summit took place during the Latin American Epilepsy Congress in San Jose, Costa Rica. This was followed by a stand-alone event, held in Dublin in 2019 for young adults from across Europe. Separate reports on these two events are available.

Three more youth summits are now being planned to take place in 2020 at the time of the regional epilepsy congresses.

Budget for 2020: €39,050

Summits in Fukuoka (30 participants), Medellin and Toronto (20 participants at each)

Venue: €8,500 Cultural programme: €13,000 Catering and materials: €14,000 Administration: €3,550.

Note that some of the costs are absorbed by the Golden Light Award budgets.





GOLDEN LIGHT AWARDS

The Golden Light award honours young people with epilepsy who have been a 'shining light' for others and deserving of recognition. The awards recognise the fact that people with epilepsy should not be defined by their condition but, instead, embrace the call of IBE to 'bring epilepsy out of the shadows and into the light'. Each bestowing of awards provides IBE with new opportunities to identify young people who have the potential to become future leaders in their own communities and as members of the IBE Youth Council.

First introduced in 2004, the awards were originally presented at each Asian & Oceanian Epilepsy congress. In 2019, the first International Golden Light awards were presented to eight recipients during the 33rd International Epilepsy Congress in Bangkok, each of whom presented their personal story of living with epilepsy during an extremely successful and moving forum. The enthusiasm of the awardees and their interest in remaining involved in IBE was the hoped-for result. Many of the young adults are now regular contributors to IBE activities, such as International Epilepsy Day, and will be invited to join the planned Youth Council.

For the future, the awards will be presented at every regional and international epilepsy congress in which IBE is involved. For 2020, Golden Lights awards will form part of the programme of the 13th Asian & Oceanian Epilepsy Congress, Fukuoka (October), the 11th Latin American Epilepsy Congress, Medellin (May) and the 1st North American Epilepsy Congress, Toronto (September).

PROCESS

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 nominated to receive an award are then invited to present their story during the Epilepsy and Society Symposium/IBE Day, 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. Every IBE chapter in the region in which the congress is taking place may nominate one recipient for the award, which are presented during the congress opening ceremony

PRIZE ENTITLEMENTS

In addition to an award trophy, pin and scroll, each candidate receives support for travel to the congress in which the award is being presented, hotel accommodation and free registration to the Epilepsy and Society Symposium/IBE Day.

Budget for 2020: €33,550

Travel support: €7,800 Accommodation: €15,400 Registration: €5,100 Awards: €2,200

Administration: €3,050



YOUTH COUNCIL

IBE recognises the importance of empowering young people with epilepsy to influence and inform the decisions that affect their lives. To this end, through the development of a Youth Council, support will be provided to young adults to get involved in their local epilepsy communities as well as at an international level, to ensure that their views are recognised and taken on board.

The IBE Youth Council plans to be the voice of young people affected by epilepsy. It will provide a platform to encourage their engagement in IBE issues and ensure their democratic participation in discussion and decision-taking on issues that directly affect them. The council will focus its work on youth policy matters within IBE, representing the views and opinions of young people affected by epilepsy. It will assist IBE in supporting self-empowerment in young people affected by epilepsy to participate actively in society, and in campaigning on issues that are important to young people with epilepsy in order to improve their own lives and to achieve their fullest potential as equal citizens.

Vision

A world in which every young adult affected by epilepsy is empowered to create positive change.

Mission

The IBE Youth Council strives to create an environment in which the views of all young adults affected by epilepsy are valued, sought and acted upon.

Our values

Participation: Young adults affected by epilepsy are forefront to the work of the council. It champions youth leadership showing the benefits of engaging young adults in decision-making and delivery on decisions taken.

Collaboration: It collaborates with all those affected by epilepsy to make positive change happen. It works to be more creative in its approach to making change happen with and for young adults affected by epilepsy, recognising the skills, knowledge and experience of these young adults and striving to achieve more through maximising the opportunities that collaboration provides.

Inclusion: It respects and values diversity and acts in a way that includes all. It ensures that all its activities are inclusive, recognising the needs of young adults affected by epilepsy across different communities and regions, and works to learn from each other.

The aims of the IBE Youth Council, as a consultative body, will be:

- To increase the participation of young people affected by epilepsy in decision-making processes within IBE and ensure that their voice is heard and acted upon;
- To promote the idea of youth policies within the IBE as an integral element of its overall policy development;
- To help to promote the exchange of ideas and experiences and to ensure that they have equal rights to their peers;
- To assist in the development of epilepsy youth groups, councils and youth work at the national and regional level in all regions of the world.

Membership

- Each IBE chapter is encouraged to nominate a young adult to the council.
- The nominee must be aged between 16 years and 30 years.
- Members of the council will elect a Youth Council Board from its members that will act as the conduit between the IBE Youth Council and the IBE International Executive Committee.
- In turn, the Youth Council Board will select from within its membership, a representative to attend IBE International Executive Committee meetings.
- Meetings of the youth council will be arranged at the time of regional and international epilepsy congresses. Other communication will be by email or other electronic format.
- Membership will cease when a member reaches the age of 30 years.

Documents profiling IBE Youth Council Terms of Reference and Working Procedures will be drafted in the near future. These will provide details on how the council will operate.

Budget for 2020