



HEAR MY STORY

Communications workshop for young adults

Talbot Hotel • Stillorgan • Dublin • Ireland
4 - 6 October 2019



An initiative of the International Bureau for Epilepsy



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A communications workshop to assist young adults with epilepsy become epilepsy advocates

Background

IBE is an international organisation for national epilepsy organisations (IBE chapters), whose mission is to improve the social condition and quality of life of people with epilepsy and those who care for them. Our core values also recognise the person with epilepsy as our primary stakeholder and all we do is focused on helping that person. We work collaboratively with our partner epilepsy related organisations, professional, lay and governmental and we are transparent and democratic in our governance and decision-making.

One of IBE's key strategic policies is to support self-empowerment of people with epilepsy to that they can attain the best possible quality of life.

Why?

In Europe, IBE represents 57 associations (our chapters) in 37 countries. There is wide recognition amongst our 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.

Those living with epilepsy face a number of additional burdens as young people. At times, they are unable to complete their education to the level they would wish; often they are unable to find a place in the workplace commensurate with their abilities; there is worry that they will not find a partner in life or create the family they might wish for; and regularly stand on the side-lines watching their peers enjoy activities in which they cannot participate. Comorbidity issues are common, with depression and anxiety being the most problematic. These comorbidities increase the epilepsy burden, which is a problem recognised by our chapters in all regions of the world.

Growing to adulthood is a difficult time for most people. For young adults with epilepsy, faced with the added issues that a diagnosis of epilepsy can bring, it can be an even more challenging time. Recognising this and in line with IBE's goal 'to provide resources for people with epilepsy and their families to maximise quality of life', a Young Adult Summit was organised in 2014. Facilitated by the IBE North American Regional Committee, the event gathered 20 young adults from Canada, Jamaica, Puerto Rico and the USA and led to the development of a media project that already has generated compelling videos telling the personal stories of triumph over adversity of young adults with epilepsy.

The success of the project is still evident in the continued active engagement of the young people in the project and in their interest in further developing the group.

How?

Building on the success of the 2014 summit, for 2019 IBE is planning the '**Hear My Story**' workshop for young adults with epilepsy living in Europe. The event will run over a weekend, from Friday 4th to Sunday 6th October, and will gather 20 young adults from across Europe who are personally affected by epilepsy. These young adults may have a diagnosis of epilepsy or may be impacted by a parent or sibling having epilepsy.

The objectives of event are:

- To provide the platform for young people to voice the issues they face and raise awareness of these issues.
- To provide young people with epilepsy with the skills to become epilepsy advocates, in partnership with our national chapters in Europe.
- To hear how young people with epilepsy perceive patient organisations and how IBE, together with our chapters, can adapt our work to better embrace the views and expectations of these young people with epilepsy.
- In Europe, the outcomes of the workshop have the potential to build to a political campaign that could be brought to national policy makers as well as those at EU level.
- Globally, we anticipate the outcomes to influence on our theme for and focus of International Epilepsy Day 2020.

The ultimate goal of the initiative is to develop a programme that assists young adults living with epilepsy to become epilepsy advocates. The pan-European initiative will engage young people from across Europe both within and outside the EU region, with the added potential to be replicated at a national level through our chapters and, with the possibility of adaption for use in other IBE regions.

Programme

IBE will organise a workshop for young adults with epilepsy entitled 'Hear My Story' with up to 20 young adults from across Europe aged 18 years to 30 years participating in a two-day event. Workshop sessions will explore ways in which the young adults can raise awareness of the issues identified by them as impacting on their ability to reach their full potential and then suggest how the young adults can use modern media avenues to solve them. Sessions will include:

- How a story, well told, has the power to influence change
- How the young person can become an advocate for change in their community
- How to use social media platforms for advocacy
- How to advocate at an EU level
- How to build and develop an online epilepsy community

Following the workshop, participants will be asked, as a team, to design and implement an advocacy project, such as a blog or online campaign, so that the momentum attained is not lost after the close of the workshop.

Who?

- Each IBE chapter in Europe is invited to nominate a candidate to attend the course.
- Participants should be under 30 years of age on 1st January 2019.
- The summit will be held in English and participants should have a good working knowledge of English.
- The candidate should be capable of travelling independently.
- First preference will be given to one candidate per chapter. Where there are more than 20 applications for places, the first 20 applicants will be chosen, with the remaining applicants forming a waiting list to fill any vacancies that might arise.

WORKSHOP PROGRAMME

DAY ONE

Arrival of delegates. A communal evening dinner in the hotel will offer the opportunity for introductions and to relax before the start of the real work on Day Two.

DAY TWO

Welcome and introductions

Ground rules, introduction to IBE and outline of goals. The workshop goals are:

- To provide participants with the platform to discuss the challenges of living with epilepsy and to identify possible solutions/projects, in particular in the digital arena, that might address these issues
- To support participants in developing skills to tell their story in a compelling manner to become advocates.
- Outline goals - to support participants in developing skills to tell their story in a compelling manner
- To identify a digital networking project that could be developed by the group to celebrate International Epilepsy Day 2020.

Discussion

The young adults will have the opportunity to share their opinions about a range of topics and themes related to epilepsy. The discussion will help in identifying a suitable project, to celebrate International Epilepsy Day, to be set up at the end of the summit. Discussion topics might include:

- stigma, myths and misconceptions, and public awareness
- how epilepsy is labelled and the inappropriate labelling
- disclosure: when to tell and who to tell about your epilepsy
- access to treatment - timely diagnosis and treatment options
- psychosocial impact and co-morbidities (cognition, memory, depression)

Wrap up of the day.

DAY 3

Having selected a digital project to develop for International Epilepsy Day, the participants will work at laying out a plan of action that will see them involved in rolling out the project over a 4-month period.

Plans for the IBE Academy will be introduced to the participants.

Closing remarks will focus on advocacy, becoming lay experts and an introduction to IBE's planned Academy.

The summit will close at mid-day to allow delegates travel home that evening.

How will we measure success?

- By measuring social engagement with the project developed by the young adults.
- By the creation of a young group in Europe with the potential for future dialogue with groups in other regions.
- By successfully engaging with young adults and engendering in them an interest in their continued involvement in the work of their national association and/or of the IBE.
- By acknowledgement by the participants of improved self-esteem and the confidence to live life to its fullest potential.
- By identifying possible future IBE leaders.

Summary

We will have achieved our goal if the initiative is successful in assisting young adults, through the provision of appropriate tools to support self-empowerment, in becoming epilepsy advocates with the confidence to advocate for change. This addresses the IBE goals to advocate for improved human and civil rights for people with epilepsy worldwide and to provide resources for people with epilepsy and their families to maximize quality of life.

The 'Hear My Story' programme will expose the young adults to the technologies, knowhow and self-belief for self-empowerment in engaging with the public, with patient groups, with the media and with the wider European community, an in advocating for change in the areas that currently adversely impact their life quality.

One of the most encouraging aspects of the project is that it identifies young people who can continue to play a part in the work of their national association and, potentially, become its future leaders or, indeed, IBE leaders.

What's covered - Expenses Policy

1. IBE will reimburse participants AFTER the event – and not before - on receipt of a completed office Expense Claim Form that is accompanied by original receipts. Photocopies will not be accepted.
2. IBE will pay up to €250 towards travel costs of each delegate. This is to include flights, parking, bus/train etc. If this amount is exceeded, the delegate (or their organisation) will be asked to cover the balance of costs.
3. Ground travel costs claimed must be public transport options; IBE will not cover private or taxi costs unless there are no other options available or where the private/taxi costs is equal to or less than the public fare.
4. IBE requests participants to choose the most economical options when making travel arrangements and will reimburse only economy class travel.
5. IBE will provide accommodation for each delegate for 2 nights in single occupancy rooms. Additional nights can be booked through IBE (subject to availability) but the cost must be borne by the participant or their organisation.
6. Catering will be provided throughout the event. Therefore, no additional food/beverages will be covered.
7. IBE requests delegates to give at least 7 days' notice of cancellation if they cannot attend. Otherwise, the delegate will be held liable for any cancellation costs incurred.

Notes:

- In exceptional circumstances, with prior agreement, the above guidelines may be waived.
- IBE reserves the right to reject expense claims that do not comply with the above rules.

Application process

Before nominating someone to attend the summit, please ensure that:

- they are interested in attending the summit
- they are available to travel on the dates indicated
- they agree to the Expenses Policy

Click [here](#) to register a participant. Closing date for registrations is Friday 6th September 2019.

Contact for further information:

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