Global Youth Summit Report 2023

A report outlining the impact of the Global Youth Summit at the IEC 2023.

IBE International Bureau for Epilepsy

In collaboration with:

Young Epilepsy

Epilepsy Ireland

Epilepsy Connections

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Alison has been an engaged advocate since she was diagnosed with epilepsy in 2006. She has a bachelor's degree from Youngstown State University and she received her Master of Public Health from the Rollins School of Public Health at Emory University.

Acknowledgements

We'd like to thank all the collaborating organizations and the staff members who supported this event. Thank you to those advocates who worked with us to plan the summit and to the family members and care partners who accompanied some of our young people. The biggest thank you goes to the 27 wonderful young people who attended, shared their experiences, stories, views, and insights, and worked together so brilliantly with such commitment, generosity, and humour. You paved the way and showed us how special and important it is to bring young people with epilepsy together!

Introduction

It was an immense privilege and a pleasure, in my role as President of the International Bureau for Epilepsy (IBE), to see our first Global Youth Summit take place at the International Epilepsy Congress in Dublin in September 2023.

I am continually impressed and encouraged by the young people with epilepsy who, despite the challenges they face, embrace these opportunities to share their experiences, learn from one another and inspire our wider community.

Change does not happen overnight, and so it is imperative that we listen to, and act upon, the viewpoints of our youth; whose tomorrows we are aiming to transform.

The perspectives gathered in Dublin, quite rightly, will inform the work of IBE now and in the years to come, and will be integrated into our flagship initiatives.

It is non-negotiable that the lived experience of people with epilepsy informs policy and decision-making, research and development, and health and social care service planning and delivery.

Therefore, it is our duty as IBE to ensure that we empower and amplify the voices of young people with epilepsy around the world, and build a new generation of advocates that will lead us to achieving our vision of a transformational social change for people with epilepsy worldwide.

My heartfelt thanks are extended to all those young people who took part, our chapters who supported the organisation of this meeting, and to the IBE team who made this important initiative a reality.

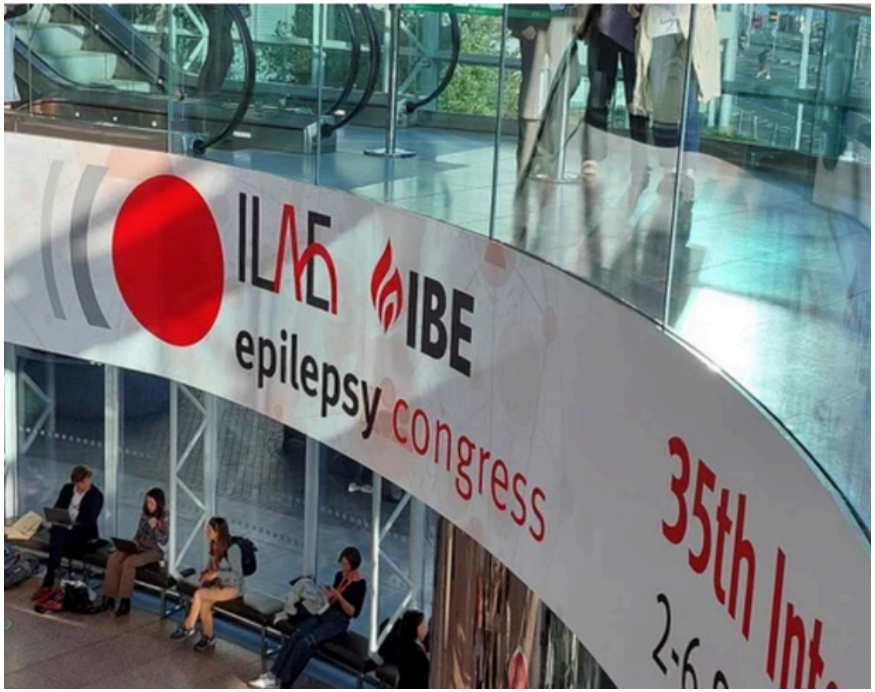
I look forward to advancing the conclusions and recommendations of this meeting together.

Dr Francesca Sofia, IBE President

Global Youth Summit

At the 35th International Epilepsy Congress

In September 2023, the International Bureau for Epilepsy (IBE), in collaboration with Epilepsy Ireland, Young Epilepsy (UK), and Epilepsy Connections (Scotland, UK), brought 27 young people with epilepsy together in Dublin, Ireland, for a Global Epilepsy Youth Summit as part of the 35th IEC.



Young people aged 19–36 from ten countries were present, including UK (England and Scotland), Ireland, Germany, Uganda, El Salvador, Chile, the United States, Canada, and Australia. The summit took place over 2.5 days during the congress.

IBE'S Youth Initiatives

IBE Global Youth Team

Working with young people living with epilepsy is a priority for IBE. The IBE Global Youth Team was launched in 2020 with the mission to encourage and support young people across the world to raise awareness and advocate for themselves and other people living with epilepsy.

Through our new strategy, launched in 2022, IBE's approach to working with young people living with epilepsy has been reinvigorated with plans to work with IBE's Global Youth Team to develop, grow, and relaunch an IBE Youth Network. The goal of the relaunched IBE Youth Network is to find new ways to connect and nurture young people living with epilepsy across the globe as young epilepsy advocates.

IBE'S Youth Initiatives

The IBE Youth Programme

Despite epilepsy being the most common chronic neurological condition in children, and with more than 50% of seizures beginning in childhood, the voices of young people living with epilepsy are often under-represented, even in advocacy and community organizations.

This, alongside being a frustrating reality for young people living with epilepsy globally, means that their biggest issues are not well understood. This makes it more difficult for organizations like IBE to support them.

The IBE Global Youth Programme will bring together young people with epilepsy, with the aims of:

- Connecting young people with epilepsy - enabling them to share their experiences and stories in a safe space
- Raising awareness of the unique experiences and challenges faced by young people with epilepsy around the world
- Ensuring that young people are represented and recognised across the epilepsy community

Global Epilepsy Youth Summit

The Youth Summit was planned by all collaborating organizations at the 35th IEC, alongside the IBE Global Youth Team and young advocates from Young Epilepsy (UK) and Epilepsy Ireland. The Epilepsy Research Institute (UK) also contributed sessions.

The sessions covered a variety of training and topics, such as challenges living with epilepsy, self-care, skill-building opportunities, and Patient and Public Involvement (PPI) in research.

Objectives

1. Connect young people living with epilepsy across the globe.
2. Explore challenges for young people with epilepsy globally.
3. Build leadership skills in young people living with epilepsy.
4. Network with each other and other stakeholders.
5. Ensure research is designed with young people living with epilepsy.

Outcomes

1. A strong, global network of young people living with epilepsy.
2. Better understanding of challenges of young people living with epilepsy.
3. Better awareness of the importance and impact of PPI in epilepsy research.

Global Youth Summit Sessions, Trainings, and Topics

Saturday Session

Introductions and Team Assignments

Throughout the Global Youth Summit, attendees were each assigned to a Home Team. As a team-building exercise, each team explored common ground. Each attendee had the opportunity to share a little bit about their epilepsy journey, explore their hopes and expectations for the summit, and start building a community among their Home Team.

Sunday Session

Exploring Challenges for Young People with Epilepsy

Understanding the specific challenges facing young people with epilepsy is vital in shaping the treatment and care, and to ensure that services and programmes across the world address those challenges.

Ahead of the summit, IBE worked with members of the Global Youth Team to develop a short, open-ended questionnaire to gather information on the most prevalent challenges experienced by young people with epilepsy across different ages.

The challenges outlined in the survey results were put into order of priority by the young people at the summit, to discuss which areas for improvement would make the biggest difference for young people with epilepsy.

Prioritization of Challenges

The Global Youth Summit attendees were given the results of the survey (see Appendix), which included the following Top 10 Challenges for Young People aged 15–34 across the 6 countries represented in the survey results:

- Social
- Employment
- Learning About and Managing your Epilepsy
- Education
- Mental Health and Well-being
- Independence
- Stigma
- Transition of Care
- Epilepsy Information and Support
- Driving

This activity made for a lively discussion around which areas impacted the Youth Summit attendees' lives the most. The group did not get through the entire top 10 list, but were able to some of the challenges in closer detail.

Social Impacts of Epilepsy on Young People

When discussing the social impacts, five themes came out of the group discussion:

A follow-up question was proposed to the group: what would help young people overcome these individual challenges?

Many suggested further **support and information** for families at diagnosis, which would also impact positively on relationships. **Public education** about epilepsy to help address stigma would be beneficial.

Attendees shared what would have helped them personally, such as **more mental health support** after diagnosis and more information on **medication side effects** (particularly behavioural).

There was a brief discussion about **dating**, specifically how some potential partners are open to learn about epilepsy, and others are not, since they don't think they'll ever witness a seizure.

It was acknowledged that each person has their **own personal challenges** living with epilepsy. One example was **driving**: some people accept they can't drive due to their epilepsy, while others still want to be able to and mourn this **loss of independence.**

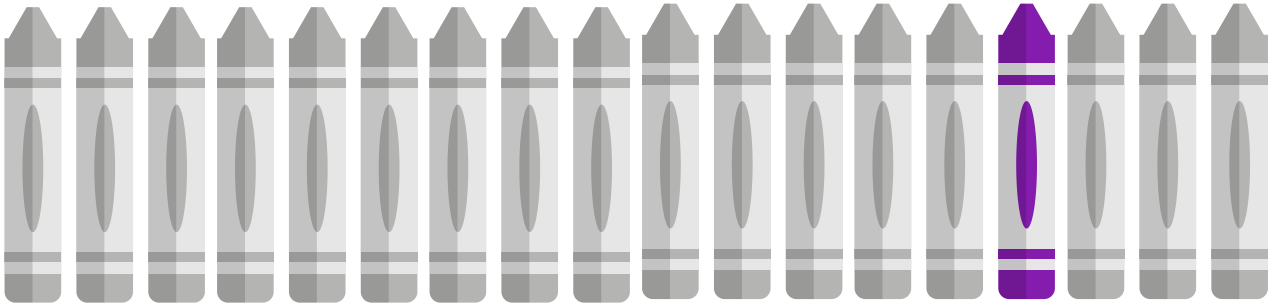
Epilepsy Stigma and Young People

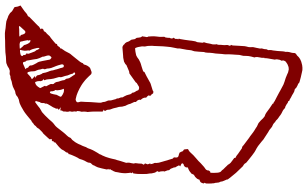
Unfortunately, it was clear in group discussion that the stigma and negative attitudes around living with seizures is still felt by members of the epilepsy community.

Historically, epilepsy has been a misunderstood and stigmatized disorder due to myths and misconceptions, especially around seizures. Anyone with epilepsy can experience stigma, even if seizures are well-controlled, and stigma can manifest in different ways.

For example, a person may not be offered a promotion because of their epilepsy, or a student may be bullied at school because of their seizures. This can lead to shame, fear, rejection, and a reluctance to seek treatment. It can also negatively impact their quality of life (Epilepsy & Behavior 2021).

If people aren't talking about epilepsy, the stigma remains: people hide their condition, and the cycle continues.





The group identified some ways to address stigma and change this narrative:

- Public health campaigns
- Education in schools, especially primary/ elementary schools
- Education and support for family and friends
- Professional presenting on employment laws
- Better representation in the media
- Policy and law-making

Mental Health and Wellbeing Challenges of Epilepsy amongst Young People

Global Youth Summit attendees shared that struggles with mental health are a deeply challenging part of their epilepsy journey.

Coping with a new diagnosis, understanding what this means, dealing with...

- The unpredictability and uncertainty of seizures (which causes significant anxiety for people with epilepsy and their family members)
- Finding the right medication and healthcare care professionals
- The impact of a diagnosis of epilepsy on your family

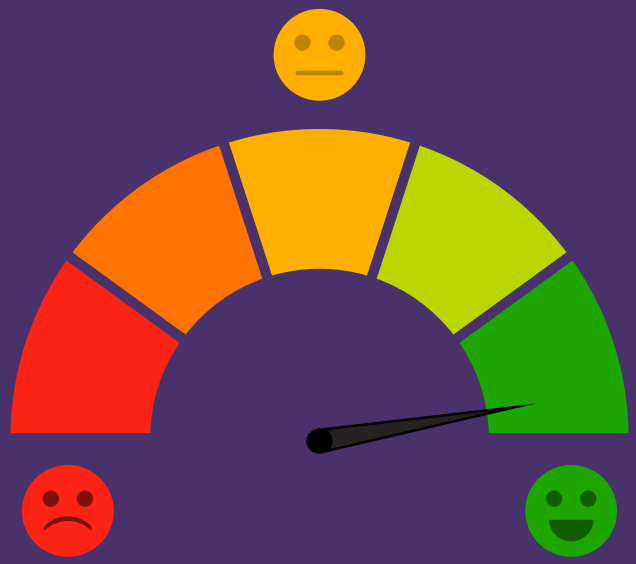
...all of which can be extremely distressing experiences for people with epilepsy.

In addition to this, all the other challenges that young people with epilepsy face contribute to their mental health burden, and can result in frustration, anger, isolation, and loneliness.

Attendees also spoke about the feeling of responsibility to change misconceptions of epilepsy among peers, colleagues, the general public, and sometimes even family members.

Whilst healthcare professionals are deeply appreciated by people with epilepsy, there was a strong sense that doctors do not focus enough on well-being more broadly.

As well as the impact of living with epilepsy itself on mental health, discussions were had about the side effects of medication and how it impacts their mental health, whether directly (e.g. causing feelings of anxiety) or indirectly (e.g. brain fog, which can affect other aspects of life).



Some members of the group shared that their healthcare providers can sometimes be quite uninformed about these factors, and therefore unable to give advice.

Attendees then brainstormed how national and international epilepsy organizations and policymakers could make a difference to mental health.

National Epilepsy Organizations:

- Provide helplines for people in the epilepsy community.
- Share information and resources on mental health and epilepsy.
- Run mental health support groups.
- Talk about mental health online and during events like conferences.
- Teach people that mental health challenges are a normal part of epilepsy.
- Educate healthcare professionals about mental health and well-being of people with epilepsy.
- Urge the prioritization of mental health in epilepsy care and treatment.

Healthcare Professionals:

- Obligatory mental health screening from healthcare professionals with referrals to psychologists where appropriate.
- Information-sharing between practitioners and psychologists to ensure consistency of care.

Policymakers:

- More funding for epilepsy and mental health.
- More funding for research into different aspects of mental health and epilepsy.

IBE:

- Drive the call for more mental health support and provision among chapters.
- Educate and share resources around medication side effects and the impact
- on mental health, and what support can be offered.

Epilepsy Information and Support for Young People

Attendees shared their frustration that healthcare professionals often focus on delivering a diagnosis without giving more information on living with epilepsy; for example, providing information on the comorbidities associated with epilepsy.

Information often emphasizes things that people with epilepsy should avoid, which can exacerbate negative feelings, particularly those who are vulnerable.

Attendees felt that healthcare professionals could do more to highlight the positives. For example, many people with epilepsy can go on to live a normal life and achieve their dreams, and whilst epilepsy is certainly challenging, it does not have to hold a person back.

Healthcare providers should act as partners to people with epilepsy, and help refer people to essential information on rights, financial benefits, and support and community organizations.

Pointing out ways for people with epilepsy to find non-medical support could go a long way in alleviating stress and anxiety at an important time.

The Global Youth Summit attendees suggested ways that key groups could address the issues of epilepsy information and support. Some of their ideas are outlined below:

Doctors and Healthcare Professionals:

- Focus more on positive messaging.
- Deliver information on non-medical aspects (e.g. mental health and quality of life).
- More information on side effects of medication.
- Link more local and national service providers and patient organizations.
- Point people with epilepsy and their families to further information on financial support.
- More acknowledgement and further training on comorbidities.

Policymakers:

- Ensure information is available for people with epilepsy and their families, particularly in the absence of a national epilepsy support organization.
- Provide financial support to people who are unable to work to support themselves.

National and International Epilepsy Organizations:

- Provide community and support groups for people with epilepsy, including a safe space for young people to meet and connect.
- Provide training on epilepsy education to different populations, such as seizure first aid training for teachers at all levels of education.

Employment of young people with epilepsy

The group discussed the challenges people with epilepsy face around employment. Whilst many challenges are universal, in countries where there is no universal healthcare and/or legislation to protect people with epilepsy, these challenges can be devastating.

Attendees spoke of other young people with epilepsy they knew who, without the protections mentioned above, were obliged to disclose their epilepsy and were subsequently turned down for work.

Much of the group felt uncomfortable disclosing their epilepsy to employers until after they had been hired. Disclosing epilepsy at work can be difficult, due to real or perceived stigma and a lack of awareness and understanding.

Attendees brainstormed how national epilepsy organizations, employers, and policymakers could facilitate people with epilepsy to feel more comfortable and safe disclosing about their epilepsy:

Employers:

- Provide epilepsy awareness and seizure first-aid training to all company representatives.
- Invest in an employees' health programme where employees can be open about any existing health condition.
- Outline and meet requirements to ensure safe working conditions and employee health & well-being, perhaps through an 'employee well-being board'.

Policymakers:

- Make seizure first aid training a mandatory requirement in workplaces.
- Ensure that first aid training includes seizure first aid.

National Epilepsy Organizations:

- Provide epilepsy awareness training to workplaces including seizure first aid.
- Campaign against stigma and discrimination in the workplace, bringing case studies to government.

Exploring Challenges for Young Men with Epilepsy

In recent years, there has been a focus on understanding the specific experiences of women with epilepsy. Whilst this conversation is essential, and is a priority topic for IBE, it is also important to ensure there is space for young men with epilepsy to share their own unique experiences and challenges.

The young male attendees were invited to sit around the same table and discuss challenges. Many experiences were shared by both young men and women. However, the topic of masculinity was specific to their experiences as young men with epilepsy.

Boys and men in general struggle to talk about their emotions, which can exacerbate the existing feelings of anxiety, stress, depression, and isolation which living with epilepsy may cause.

Group members shared insights into how epilepsy could have an impact on fitting into traditional descriptions of masculinity. The notion that living with epilepsy may impact stereotypically masculine ideals, like strength and being a provider, may stop young men with epilepsy asking for help and sharing their experiences and feelings.

One attendee shared how his support network helped him feel confident to talk about epilepsy. Some members of the group also spoke about how sport, specifically football, and teammates had helped them.

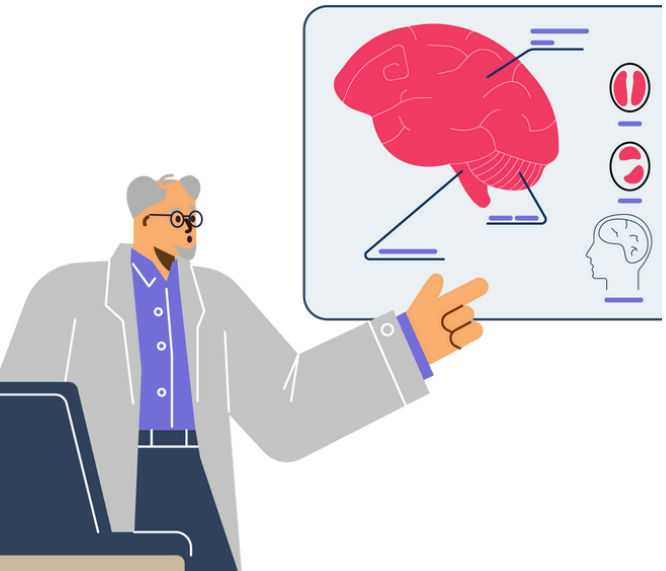
Sunday: Other Sessions

Other sessions held during the Global Youth Summit focused on skill-building, so the participants could better care for their epilepsy.

Exploring Self-Care in Epilepsy

This session was delivered by Niamh Jones, Community Resource Officer from Epilepsy Ireland and focused on the individual living with epilepsy.

This was a relaxing, light-hearted session, where participants could improve their skills in understanding themselves, their lives and their epilepsy. In this session, youth summit attendees explored self-care habits and healthy boundaries. Each participant identified ways to work towards one small positive change they could make.



Epilepsy Research: the past, present and future

In the final session of this day, Professor Matthew Walker, eminent neurologist and researcher at University College London, gave an overview of the scienc of epilepsy and took participants through a presentation exploring epilepsy research including significant past and present research, and what the epilepsy research of the future looks like.

Monday Sessions

The final day of the Global Youth Summit saw three sessions delivered by Epilepsy Research Institute UK. Participants explored the importance of PPI in research. It was a new topic for some of the participants, so the sessions allowed for an engaging discussion among the group.

EPILEPSY RESEARCH INSTITUTE UK

An Introduction to PPI in Research

Part 1 explored examples of where people with epilepsy can work with researchers to strengthen epilepsy research. This session was delivered by Annee Amjad, Epilepsy Research Institute UK, alongside researcher Dr Gareth Morris, Senior Research Fellow and epilepsy researcher, University College London.

Part 2 was an interactive practice session that looked at epilepsy research proposals and discussed how these studies could be designed in collaboration with people affected by epilepsy.

PPI in Data and Developing Outcome Measures

This part explored examples of how PPI Data has been used, its importance in research, and how to create outcome measures. Two IBE Global Youth Team members, Lorraine Lally and Leonie Wollscheid shared their experience of working alongside researchers and healthcare professionals to develop new outcome measures for epilepsy.

Summary and Feedback

The Global Youth Summit was a special event that brought together a strong, global network of young people living with epilepsy who were able to deeply connect with each other, share experiences, and offer each other understanding and support.

Across the 2.5 days, Global Youth Summit attendees:

- Explored the challenges affecting young people with epilepsy across the world.
- Discussed the importance of self-care in the management of epilepsy.
- Learned about the science and research of epilepsy and PPI.

The attendees were asked to share feedback about the summit, with overwhelmingly positive feedback.

"It provided several cross-continental connections and showed the participants may have different stories, but they share similar experiences."

"Built a sense of community and a safe space to be yourself and share"

"[An opportunity to] hear other stories and know you're not alone."

In response to suggestions for improvement from the attendees, and looking ahead to future Global Youth Summits, the planning team would keep the days shorter, ensure all presentations were in plain English, keep sessions as interactive as possible, and utilize the time we have best for presentations and discussion.

Next steps for IBE

Regional virtual workshops

The Global Youth Summit allowed IBE to reflect on the topics discussed, and understand how important it is to ensure young people with epilepsy from around the world can connect and learn from each other, share their experiences and understand both global commonalities and region-specific challenges. IBE will take learnings from the Global Youth Summit to shape workshops with young people with epilepsy across its working regions around the world: Europe, North America, Latin America, Africa, South East Asia, and the Western Pacific.

Joint initiative with YES

As a result of the Global Youth Summit, the IBE's Global Youth Team will be working closely with the International League Against Epilepsy's (ILAE) Young Epilepsy Section to plan and deliver a workshop between young people with epilepsy and neurologists and epileptologists to discuss the experiences of young people with epilepsy when it comes to medical care, to be delivered in late 2024.

Global Epilepsy Leaders Programme

This is a new programme, launching in August 2024, focused on developing our advocates and chapter leaders of the future. The pilot will be developed in collaboration with our community, and last approximately 12 months. The programme aims to equip epilepsy advocates and chapter representatives with the skills, experience and confidence to become leaders in the epilepsy field – nationally, regionally, and globally. Please get in touch for more information if you are interested in learning more.

IBE International Bureau for Epilepsy

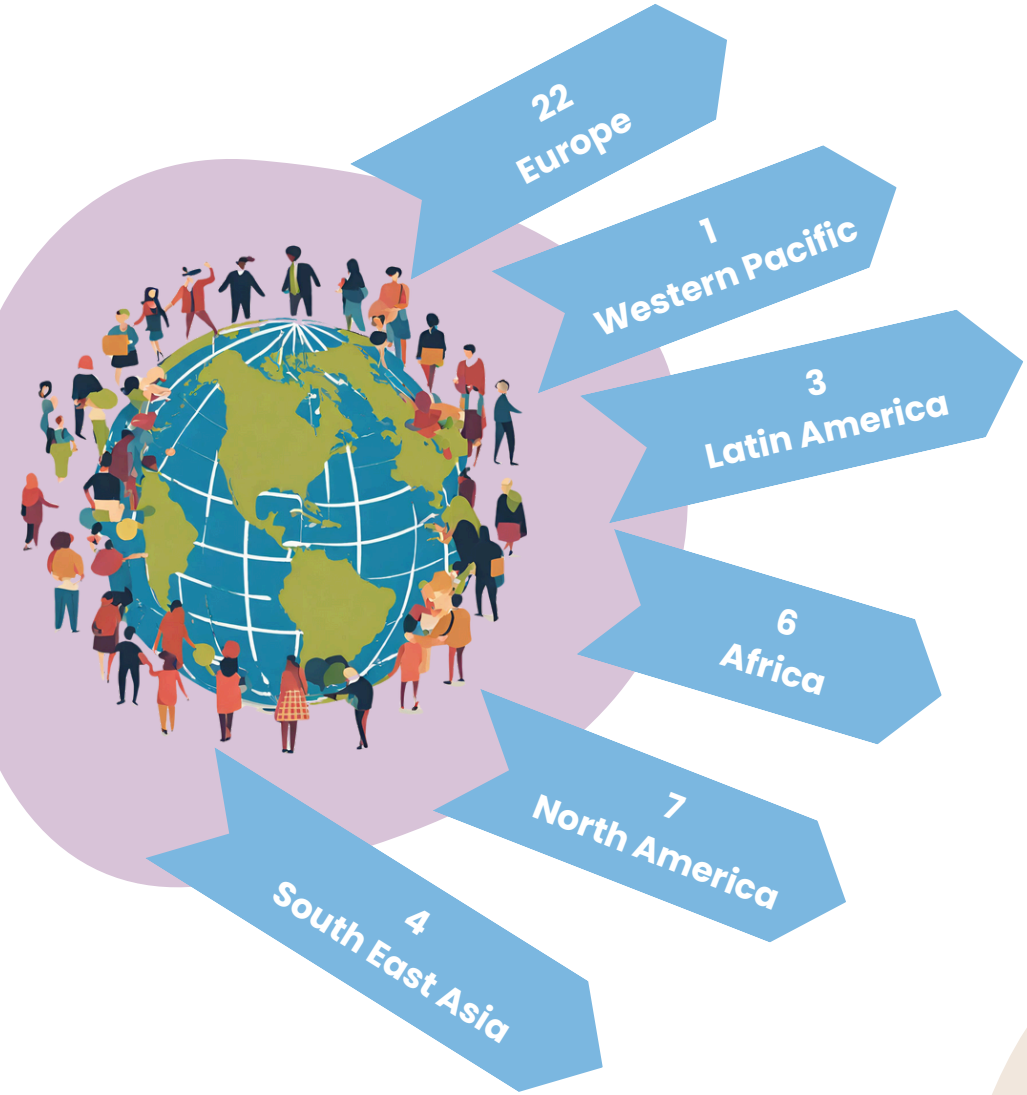
Get in touch

If you would like to know more about the Global Youth Summit or any of the IBE activities mentioned, please contact: support@ibe-epilepsy.org.

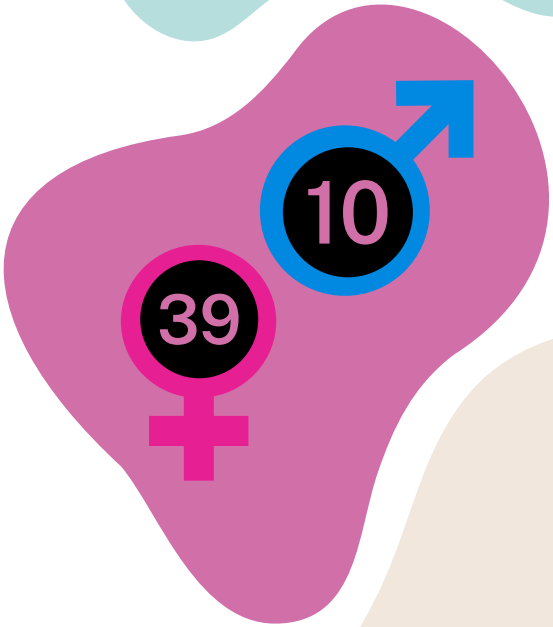
The youth summit was made possible due to grants/sponsorship for IBE-INVOLVE from the following:

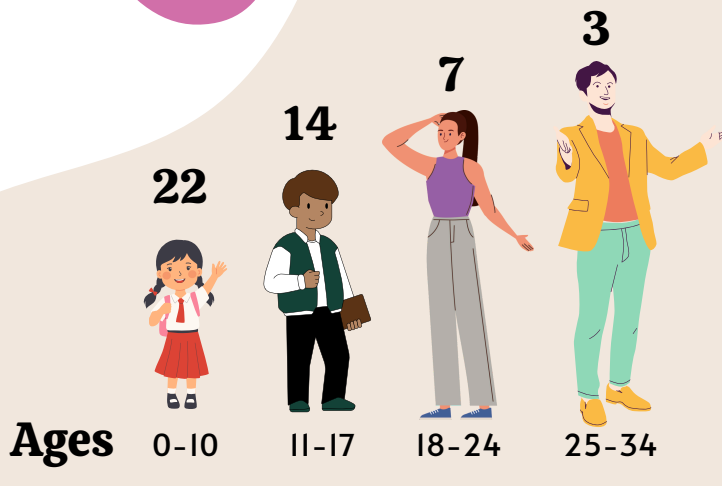
Appendices:

1.1 Results from questionnaire administered ahead of Youth Summit. Who we heard from:



49 People

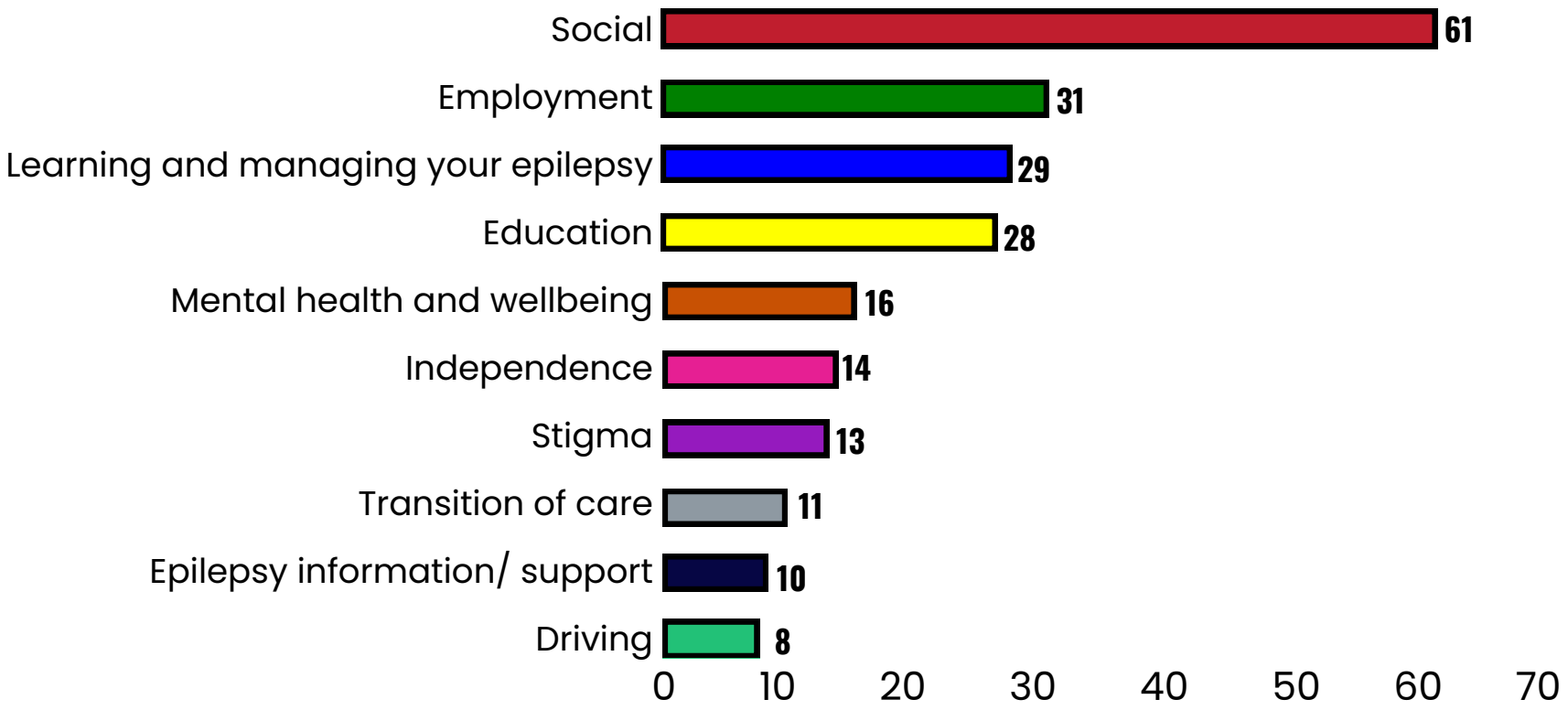




1.2 Respondents shared challenges related to these themes

- Social
- Stigma
- Marriage
- Having a family
- Discrimination
- Sleep
- Memory
- Education
- Mental Wellbeing
- Addiction
- Physical wellbeing
- Transition of care
- Driving
- Impact on family relationships
- Employment
- Availability/ cost of medication
- Epilepsy information & support
- Alcohol
- Impact on life decisions
- Learning/ managing epilepsy
- Expectations of YPWE
- Adherence to medication
- Social
- Understanding of epilepsy

1.3: Respondents Top 10 Challenges for Young People ages 15–34



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