

ILAE



IBE

epilepsy congress

35th International  
2-6 Sept

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# 35th International Epilepsy Congress

Organised biennially by the International League Against Epilepsy (ILAE) and International Bureau for Epilepsy (IBE), the International Epilepsy Congress (IEC) stands as the most significant global scientific gathering focused on epilepsy.

The 35th IEC took place from 2 – 6 September 2023 at the Convention Centre in the heart of Dublin, Ireland.

As President of the International Bureau for Epilepsy, I firmly believe that we will not change the lives of people with epilepsy unless we truly understand what matters most to them; unless we truly understand how research and clinical practice can, and should, be focussed on addressing the most pressing burdens.

At IEC 2023, I was so pleased to see people with epilepsy and those who care for them, given a platform in the main and parallel sessions to ensure we ground the science in the real, lived experience of our community. It is not enough, though, for the science to stay within the walls of the congress centre, or the pages of our scientific journals, and so I was honoured to open the first of two public sessions – organised by, our chapter, Epilepsy Ireland – where over 200 people had registered each evening, with another 200 people from around the world signed-up to following the livestream. The enthusiasm of the scientific community to come and speak at these events was heartening. Supplemented by our Citizen Journalists who reported online about the congress activities, this was truly a great effort to disseminate the latest science to all those people living with epilepsy; providing hope.

Hope was also provided through a gathering of young people with epilepsy from all across the world who came to join our first-ever Global Epilepsy Youth Summit, by the convening of our chapters from across the globe – sharing their experiences and achievements, by those who turned up to a teaching course on Patient and Public Involvement, and by a Presidential Symposium focussed on defining meaningful outcomes which attracted such a large audience. I am hopeful that IEC 2023 will set a precedent for the engagement of people with epilepsy in future congresses, and I look forward to seeing this grow even further!



Patient and public involvement is a concept that we have been talking about for many years. However, at this – the 35th International Epilepsy Congress – I believe that we have moved beyond talking, and the meaningful engagement of people with epilepsy was demonstrated throughout the programme.



Dr Francesca Sofia, IBE President

# Amplifying The Voices of Lived Experience

## #EpilepsyVoices

To amplify the voices of lived experience during IEC we registered a dedicated hashtag, #EpilepsyVoices at Symplur's Healthcare Hashtag Project, encouraging its use alongside the official #IEC2023 hashtag.

### Healthcare Hashtag Project

Healthcare Hashtag Project, a free open platform for patient advocates, caregivers, doctors and other providers that connects them to relevant conversations and communities.



### The Community by the Numbers

2,000,000,000+ Tweets  
 25,288 Hashtags  
 18,620 Topics  
 7,511 Contributors

### #EpilepsyVoices Social Media

Found 1 results for "#EpilepsyVoices"

### #EpilepsyVoices Hashtags 1 of 1

Hashtag	Type	Description
#EpilepsyVoices	Disease Hashtags	Caregiver Support, genetic epilepsy, lived experience, patient advocacy, Patient-Centered Care, patient empowerment, patient experience

[Home](#) / [Healthcare Hashtags](#) / [#EpilepsyVoices](#) / [Analytics](#)

### The #EpilepsyVoices Influencers

#### Top 10 Influential

- @IBESocialMedia 100
- @lIaeWeb 67
- @LoriWolffHeffner 60
- @EpilepsyTz 50
- @lorraine\_lally 55
- @purplebenchug 36

#### Prolific Tweeters

- @lorraine\_lally 10
- @IBESocialMedia 9
- @lIaeWeb 3
- @LeavyYvonne 2
- @KetteValentic 1
- @BetsyPilon 1
- @EPICLongIsland 1
- @AWilkinsBioExec 1
- @nandanyardi 1

#### Highest Impressions

- @IBESocialMedia 29.1K
- @lIaeWeb 21.1K
- @lorraine\_lally 14.3K
- @EPICLongIsland 5.8K
- @NehaDietitian 812.0
- @BetsyPilon 540.0
- @dpfloyd 488.0
- @LeavyYvonne 272.0
- @AWilkinsBioExec 247.0

The hashtag garnered close to 73K Impressions.

### The Numbers

72.968K Impressions  
 42 Tweets  
 16 Participants  
 2 Avg Tweets/Hour  
 3 Avg Tweets/Participant

# Social Media

We experienced exponential growth in the days leading up to IEC and during the Congress itself.

## 28 day summary with change over previous period

Tweet impressions

120K ↑965.7%

Followers

3,255 ↑87



### Page overview

[Create a post](#)

Last 28 days

### Discovery

Post reach	2,332
Post engagement	606
New Page likes	29
New Page Followers	43



## Analytics ?

Last 30 day activity



270 ▲ 42.1%

Search appearances

Last 7 days

102 ▲ 67.2%

Unique visitors

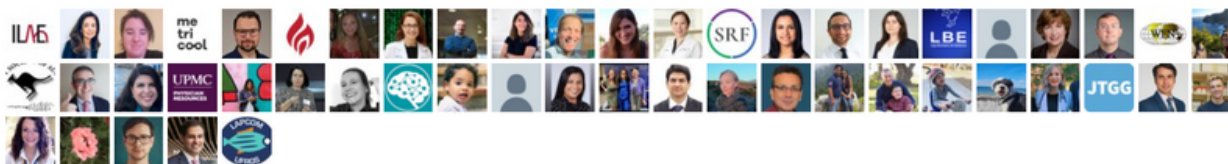
84 ▲ 86.7%

New followers

8.9K ▲ 54.1%

Post impressions

## #IEC2023 Participants



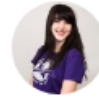
# Bringing The Voice of Lived Experience To #IEC2023

Epilepsy isn't just a medical condition; it's a journey that profoundly impacts individuals and their families.

Understanding the medical aspects of epilepsy is crucial, but understanding the emotional, psychological, and social elements is just as important.

A key focus of this year's International Epilepsy Congress was the inclusion of speakers with lived experience. These speakers grounded the Congress in real-life experiences, reminding attendees that every data point represents a life, a family, and a unique journey.





Cassidy Megan • 1st

Founder of Purple Day

2d • 🌐

Thank you **INTERNATIONAL BUREAU FOR EPILEPSY** and **International League Against Epilepsy** for having speakers with Lived Experience at the **#IEC2023** and thank you to all who shared their **#LivedExperience**



Alison Kukla, MPH (She/Her) • Following

Senior Manager, Programs and Partnerships at Epilepsy Foundation

22h • 🌐

I was honored to speak at the International Epilepsy Congress and have Preston join to share his perspective as a caregiver. We shared how nurses have impacted our journey with epilepsy and how they are true super heroes. It was so important to have the **#EpilepsyVoices** at the Congress and I'm grateful they were incorporated throughout the Congress.



Yvonne Cahalane

September 5 at 6:45 PM • 🌐

The day isn't over yet, but it was a fantastic one.

Thank you for the support from the entire panel, acknowledgements from the medical professionals in the auditorium & the support from all the **Epilepsy Ireland ILAE - International League Against Epilepsy International Bureau for Epilepsy & YEAH - Young Epilepsy Advocates Hub**



# Citizen Journalists

This innovative addition infused IEC 2023 with fresh perspectives. The participation of citizen journalists brought the voice of the people with direct experience of epilepsy to the forefront.



As a citizen journalist at the International Epilepsy Congress my goal is to highlight the issues that matter most to people living with epilepsy.

**Jessie Nyirenda**  
ZAMBIA

#EpilepsyVoices

#IEC2023



As a citizen journalist I can provide a powerful voice on behalf of persons with epilepsy, their caregivers, and their families during #IEC2023

**Deirdre Floyd**  
CANADA

#EpilepsyVoices

#IEC2023



As a citizen journalist at the 2023 International Epilepsy Congress I hope to amplify the voices and experiences of caregivers through sharing my experiences.

**Preston Reilly**  
USA

#EpilepsyVoices

#IEC2023



Citizen journalism is a powerful way for me to give a voice to people with epilepsy, their caregivers, and their families during #IEC2023.

**Anita Mago**  
UGANDA

#EpilepsyVoices

#IEC2023



## Citizen Journalism

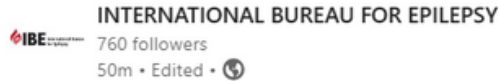
at

35th International  
Epilepsy Congress

2- 6 September 2023

#EpilepsyVoices

#IEC2023



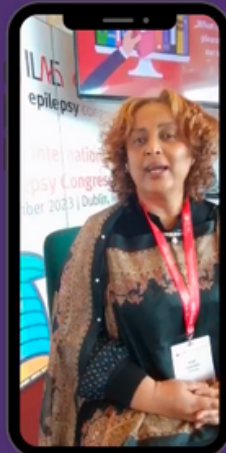
Check out this inspiring video interview featuring [Enat Yewnetu](#), the visionary behind [CareEpilepsy](#) Ethiopia.

Our citizen journalist, [Jessie Phelile Nyirenda](#) brings you an inside look at this charitable organization's mission to enhance the quality of life for individuals impacted by [#epilepsy](#) in [#Ethiopia](#). From medical care to combating stigma and social obstacles, promoting well-being, conducting research, and bolstering healthcare professionals' capacity, CareEpilepsy Ethiopia is making a real difference.

[#EpilepsyAwareness](#) [#CharityWork](#) [#Epilepsy](#)

*Enat Yewnetu*

Founder  
CareEpilepsy  
Ethiopia



Thanks to Citizen Journalist [Anita S. Mago](#) for this interview with Angela McCarthy, Mom to [Cassidy Megan](#). Angela was one of our lived experience speakers at the recent International Epilepsy Congress (IEC) in Dublin.

In this brief interview, Angela emphasizes the significance of including individuals with lived experiences as conference speakers and conference participants. She also highlights the transformative and inspiring nature of the Youth Summit at IEC, where young people from diverse backgrounds gathered to collaborate and exchange ideas.

[#epilepsyawareness](#) [#caregiver](#) [#epilepsyvoices](#)

*Angela McCarthy*

Caregiver  
Lived Experience Speaker



Our citizen journalists were out and about at [#IEC2023](#) capturing the voices of attendees. We loved hearing from Devesh Kumar, Senior Scientist at UCB about how much he enjoyed directly hearing from patients and caregivers about life with [#epilepsy](#)

[#EpilepsyVoices](#)

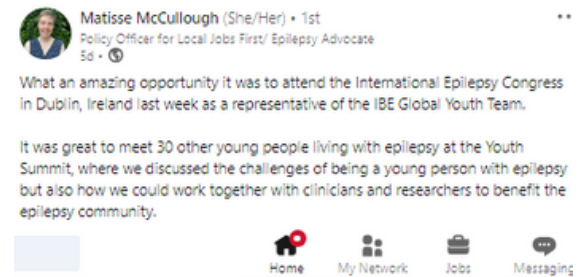


# Youth Summit

A group of young people (18-35) living with epilepsy came to Dublin to participate in our first-ever Epilepsy Youth Summit. The aim was to connect young people living with epilepsy to share their experiences and explore common challenges. Sessions also focused on building leadership skills, learning more about epilepsy research, engaging in personal development activities, and networking with each other and other stakeholders. The feedback was overwhelmingly positive, with many attendees declaring it to be a life-changing experience!



**Andrea L. Wilkinson** (She/Her) • Following  
Board of Directors, Project Open Hand & Global Epilepsy Head of Patient E...  
The future is in the hands of this talented group of [#epilepsyvoices](#)



# Networking at IEC

There were plentiful opportunities to network and exchange fruitful ideas during IEC. Attendees also discovered a sense they were not alone in the vital work they do.



**Adam Jallow Janneh** • 2nd  
President and Cofounder of FESS-Gam/MSDG:DDF Fellow/Epilepsy Advocat...  
2w • Edited • 🌐



Being an epilepsy advocate in Africa can sometimes feel very lonely. No matter how many times you answer the question "why epilepsy?" people look at you strangely. I'm at the 35th International Epilepsy Congress in Dublin and yes the feeling is overwhelming seeing the many numbers of people that have taken time off their busy schedules for epilepsy from across the globe. I'm a proud epilepsy advocate



**Global Organization of Health Education (GOHE)**

636 followers  
17h • Edited • 🌐

The International Epilepsy Congress was an amazing opportunity to meet up with many colleagues who share our focus on narrowing [#epilepsy](#) treatment gaps globally. Can't wait to do it again in 2025!



**Anita S. Mago** • Following  
Program Director at Purple Bench Initiative  
1d • 🌐



The feel of East Africa in iec2023 Dublin. Fides Auiso -Tanzania, Fred Beuchi - Kenya and Nina Mago - Uganda. After Congress sessions the trio often got together to see how issues discussed apply to their local situations.



# Public Sessions

An exciting development this year was the inclusion of a special public program, arranged by Epilepsy Ireland, held over two evenings.

The program featured renowned epilepsy experts who presented their research and findings in a way that was accessible for all.

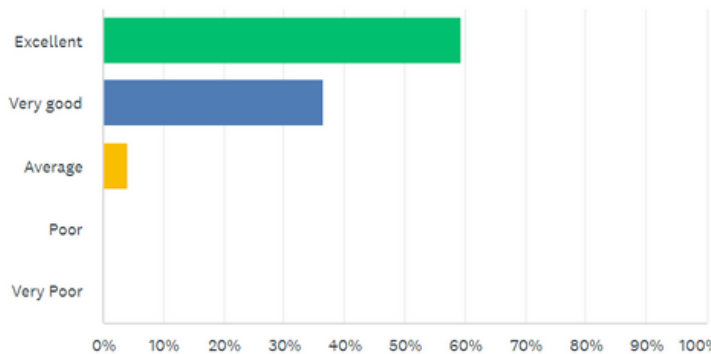


# Public Sessions Feedback

The feedback survey conducted by Epilepsy Ireland clearly indicated an overwhelmingly positive response to the Public Sessions.

## Overall, how would you rate our public sessions at the Interna...

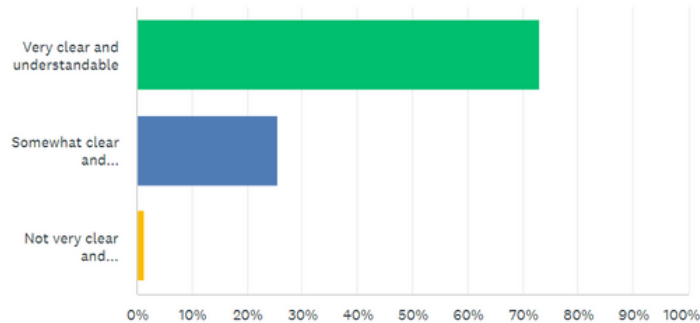
Answered: 74 Skipped: 14



I want to express my appreciation for the effort and time you put into making the latest research on epilepsy available to the public. Everything was excellent, and I look forward to attending more events like this. Congratulations!

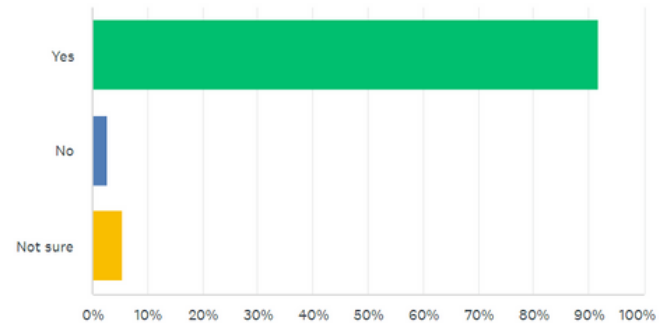
## Overall, did you feel that the speakers presentations were cle...

Answered: 74 Skipped: 14



## Did you learn anything new from the information that was pre...

Answered: 74 Skipped: 14



# Golden Light Awards

Three inspiring young people – from Brazil, Tanzania and Ireland – were selected to receive this year's award, from over 20 nominations received from across the world. The Awards are an opportunity to recognise and reward outstanding young people who live with epilepsy or care for a person with epilepsy.



# Social Accomplishment Award

The Social Accomplishment Award is given to an individual to recognise his or her outstanding personal contribution to activities that have resulted in a significant advance in the social well-being and or quality of life of people with epilepsy.

This year the Award was given to 24-year-old Cassidy Megan, from Nova Scotia, Canada. Cassidy is the founder of Purple Day, an epilepsy awareness day that is recognized and celebrated globally every year on March 26.

Cassidy is also a member of IBE's Global Youth Team and played an active part in the Youth Summit at IEC.



# The Curse of Stigma

The first screening of an exclusive preview of the documentary film *The Curse of Stigma* took place at IEC 2023.

A powerful and intimate documentary film that tells the story of two African women living with epilepsy and the pain, isolation, and harm they have suffered because of discrimination and deeply embedded cultural beliefs.

Their ultimate understanding of epilepsy as a treatable condition leads them to better health and brighter futures. By telling their truth, and the truth about epilepsy, they overcome shame – the ultimate curse of epilepsy stigma.

The BAND Foundation and the Whitten-Newman Foundation jointly produced this film to raise awareness of the challenges of living with epilepsy in Africa and the opportunity to address stigma and advance access to affordable treatment. Funds raised through this effort will go directly to IBE Africa's Anti-Stigma Campaign.

**For more information visit: [thecurseofstigma.org](https://thecurseofstigma.org)**



