

# Raising Patient Voices: A Descriptive Analysis Measuring the Representation of Patient Experiences and Perspectives in Neurology and Epilepsy Conferences

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## Introduction

- Medical conferences provide a collaborative platform for the medical community to discuss patient-centric approaches to research, such as improving clinical trial recruitment and evaluating patient-reported outcomes
- However, patient involvement in medical conferences remains underrepresented, with approximately 25% of conferences in Europe and 20% in North America actively including patients in conference-related activities<sup>1,2</sup>
- Patients affected by chronic and high-burden conditions such as neurological diseases and epilepsy may benefit from first-hand experiences at medical conferences, which may educate them about their condition and treatment options as well as allowing them to build relationships with healthcare professionals<sup>3,4</sup>

## Objective

To evaluate how patient experiences and perspectives are represented within research presented at major neurology and epilepsy conferences

## Methods

- In this descriptive analysis, 7 neurology and 3 epilepsy global congresses (N=10) were identified based on attendance
- A literature search using the BIOSIS Previews, Embase, MEDLINE, and Northern Light databases was conducted to quantify abstracts on (but not limited to) disease burden, patient-reported outcomes, patient surveys, and patient perspectives of clinical trials and treatment (Figure 1)

Figure 1. Literature Search Parameters

(cfti("Conference Name") AND (ti(Patient) AND ti.ab,if((empower\* OR activat\* OR engage\* OR enabl\* OR involve\* OR participation OR centered\* OR orientation OR self-management OR self-care OR shared decision making\* OR adherence OR compliance)) NOT ti(trial)) NOT ti.ab("case report\*" OR (randomized and trial\*)))



ti.ab,if((patient and perspective) OR (patient and experience) OR (patient and perception) OR (patient and engage\*) OR (patient and satisf\*) OR survey OR "patient reported outcome\*" OR "disease burden") NOT (pharmacokinetics))

Ab, abstract; Cfti, conference title; If, keyword; Ti, title.

- Results from 2020 to 2025 were reported to assess trends over time
- Abstracts at each congress were further categorized into subtopics, including:

- Patient-reported outcomes and patient perspectives
- Patient decision-making, patient advocacy groups, and patient education
- Clinician perspectives

## Results

- The most highly attended global neurology and epilepsy conferences and their key characteristics are summarized (Table 1)
- The American Epilepsy Society (AES) Annual Meeting was the only conference with a patient-focused abstract submission subtrack: Partners Against Mortality in Epilepsy (PAME)

Table 1. Key Characteristics of Highly Attended Neurology and Epilepsy Conferences

Conference Name	Primary Focus	Number of Attendees	Meeting Frequency	Where Abstracts Are Published (Impact Factor)	Patient Registration Offered?	Patient-Focused Subtracks
<b>Neurology</b>						
Society for Neuroscience (SfN) Annual Meeting	Neuroscience /Neurology	27,000	Annual	Journal of Neuroscience (4.0)	No	NA
American Academy of Neurology (AAN) Annual Meeting	Clinical Neurology	13,000	Annual	Neurology (9.0)	No	NA
European Academy of Neurology (EAN) Congress	Clinical Neurology	8,289	Annual	European Journal of Neurology (3.9)	No	NA
Federation of European Neuroscience Societies (FENS) Forum	Neuroscience	7,300	Biennial	European Journal of Neuroscience (2.4)	No	NA
World Congress of Neurology (WCN)	Global Neurology	4,000	Biennial	Journal of the Neurological Sciences (3.2)	No	NA
International Child Neurology Congress	Pediatric Neurology	1,500	Biennial	Journal of the International Child Neurology Association (N/A)	No	NA
Child Neurology Society Annual Meeting	Pediatric Neurology	1,000	Annual	Annals of Neurology (7.7)	No	NA
<b>Epilepsy</b>						
American Epilepsy Society (AES) Annual Meeting	Epilepsy	5,500	Annual	Abstracts published on aesnet.org	Advocates/family members attend at a reduced rate	PAME
International Epilepsy Congress (IEC)	Epilepsy	4,000	Biennial	Epilepsia (6.6)	Option to attend as member/nonmember patient advocate	NA
European Epilepsy Congress (EEC)	Epilepsy	3,600	Biennial	Epilepsia (6.6)	Option to attend as member/nonmember patient advocate at EEC 2024	NA

Impact factors were gathered from journal websites. NA, not applicable; PAME, Partners Against Mortality in Epilepsy.

- Across the search period, the American Academy of Neurology (AAN) Annual Meeting and AES had the most abstracts that met the prespecified criteria of patient-focused content among the neurology and epilepsy conferences evaluated, respectively (Table 2)

Table 2. Patient-Focused Abstract Output by Congress, 2020–2025

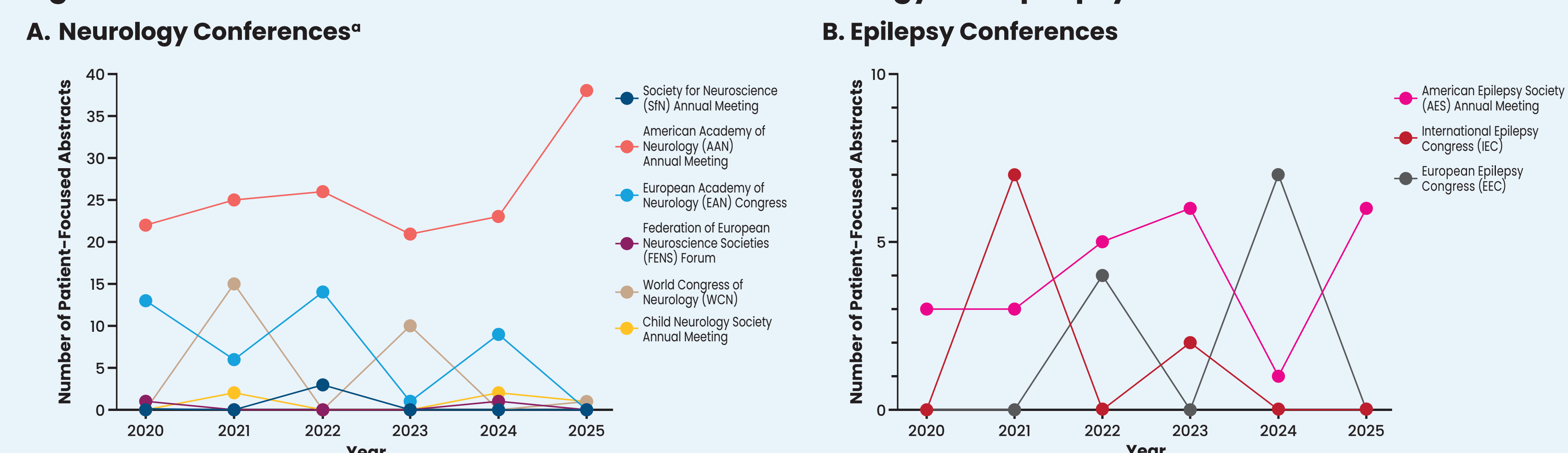
Conference Name	Number of Patient-Focused Abstracts
<b>Neurology</b>	
American Academy of Neurology (AAN) Annual Meeting	155
European Academy of Neurology (EAN) Congress	43
World Congress of Neurology (WCN) <sup>a</sup>	25
Child Neurology Society Annual Meeting	5
Society for Neuroscience (SfN) Annual Meeting	3
Federation of European Neuroscience Societies (FENS) Forum <sup>a</sup>	2
International Child Neurology Congress <sup>a</sup>	NE <sup>b</sup>
<b>Epilepsy</b>	
American Epilepsy Society (AES) Annual Meeting	24
European Epilepsy Congress (EEC) <sup>a</sup>	11
International Epilepsy Congress (IEC) <sup>a</sup>	9

<sup>a</sup>Conferences are held biennially (every 2 years). <sup>b</sup>Number of abstracts in the International Child Neurology Congress not reported, as these abstracts were not indexed in the MEDLINE, Embase, BIOSIS, or Northern Light databases and therefore are not readily searchable.

NE, not evaluable.

- Throughout 2020–2025, both AAN and AES demonstrated general increases in the number of patient-focused abstracts (Figure 2)

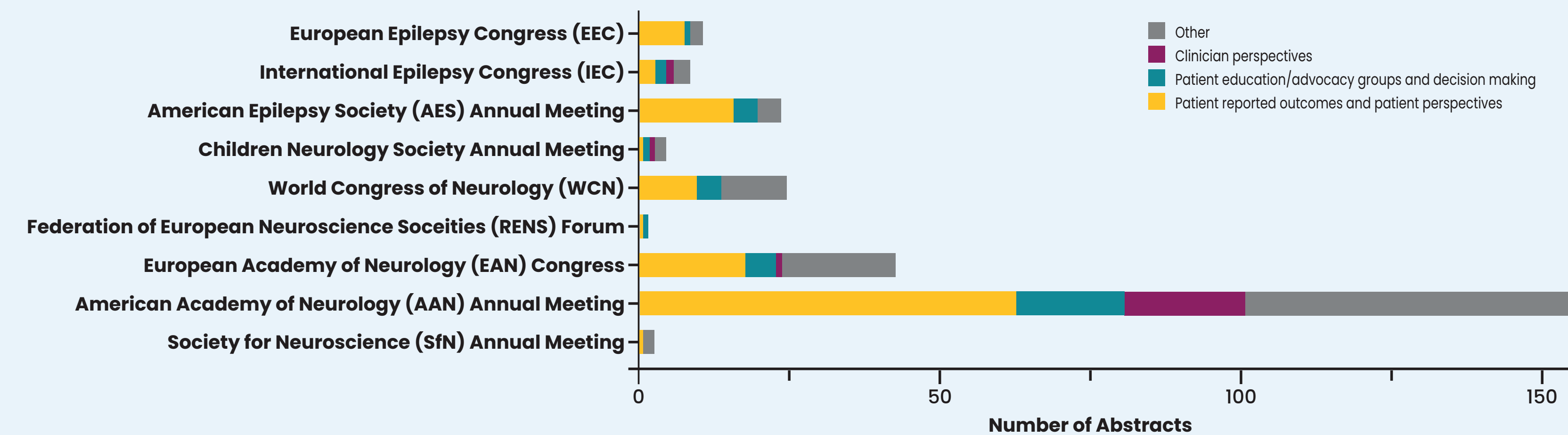
Figure 2. Number of Patient Focused Abstracts for Neurology and Epilepsy Conferences, 2020–2025



<sup>a</sup>Number of abstracts in the International Child Neurology Congress not reported, as these abstracts were not indexed in the MEDLINE, Embase, BIOSIS, or Northern Light databases and therefore are not readily searchable.

- In these conferences, a majority of patient-focused content described patient-reported outcomes and patient perspectives detailing disease burden, quality of life, and treatment satisfaction (Figure 3)

Figure 3. Abstract by Subtopics in Neurology and Epilepsy Conferences, 2020–2025



Number of abstracts in the International Child Neurology Congress not reported, as these abstracts were not indexed in the MEDLINE, Embase, BIOSIS, or Northern Light databases and therefore are not readily searchable.

- Among all abstracts identified in the search, one abstract from AAN listed a patient author in the author affiliations

## Limitations

- Key terms in the literature search may have excluded additional patient-focused abstracts
- Possible overlap in the number of abstracts at each conference due to encores
- Abstract subtopics were manually categorized based on the conference material title and abstract, raising the potential for bias in categorizing these abstracts
- Missing data for the International Child Neurology Congress because abstracts were not indexed or easily searchable within the ICNC database

## Conclusions

- In this analysis, patient-focused content was well-represented at AAN and AES and generally increased over the last 5 years
- The AES Annual Meeting was the only conference with a designated patient-focused subtrack, Partners Against Mortality in Epilepsy (PAME)
- Since some global and European neurology and epilepsy conferences are held biennially, there was limited representation and decreasing trends observed in patient-focused content based on this analysis's search parameters
- Increased patient-focused content in conferences may help reduce gaps in medical education and improve understanding of patient perspectives

## References

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