



# AGENDA

**April 24 and 25, 2025**

## 2025 Research Roundtable for Epilepsy: Measuring Seizure Impact Beyond Counting

### Meeting Objectives:

- Determine what we may be missing from just counting seizures
- Identify where EEG vs diary count vs. both is appropriate for different seizure types
- Outline the place of wearable devices as outcome measures in trials
- Propose potential outcomes assessments that capture seizure impact

### DAY 1 – Thursday, April 24, 2025

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8:00	REGISTRATION and BREAKFAST	
9:00 – 9:15	Meeting Welcome & Updates	
9:00 – 9:10	Welcome, Meeting Goals, and Deliverables	Caitlin Grzeskowiak, Bernice Lee
9:10 – 9:15	Updates on Previous RRE Topic	Jacqueline French, Nathan Fountain, Billy Dunn
9:15 – 9:30	2025 Challenge and Overview	
	Topic introduction	Jacqueline French. Nathan Fountain
9:30 – 11:10	Session I: Issues with Seizure Counting	
9:30 – 9:40	Lived Experience	Cara Abercrombie and Bina Maniar
9:40 – 9:55	Difficult to count seizures – difficulty with counting atypical absence, absence, tonic / atonic without fall	Sudha Kessler
9:55 – 10:10	Challenges with long term seizure counting – difficulty with maintaining a seizure diary over six months or more	Dan Friedman

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**10:10 – 10:25      BREAK**


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10:25 - 10:40	Accuracy of seizure diary counts (nocturnal seizures, unwitnessed seizures)	Bob Fisher
10:40 – 10:55	Issues with diseases where not everyone experiences seizures, or seizures are a secondary outcome (e.g., S-check)	Caitlin Grzeskowiak
10:55 – 11:10	Burden of disease beyond seizure counting	Kate Davis
11:10 – 11:40	Open Discussion	

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**11:40 – 12:30      **Session II: When is ictal EEG / EEG based seizure counting device suitable as an outcome measure?****

11:40 – 11:55	Stage setting	Nathan Fountain
11:55 – 12:10	Absence	Dennis Dlugos
12:10 – 12:30	Focal Seizures	Dan Friedman

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**12:30 – 1:30      LUNCH**


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1:30 – 3:00	<b>Session II Continued</b>	
1:30 - 1:45	Tonic Clonic	Nathan Fountain
1:45 – 2:05	Seizures associated with DEE	Helen Cross
2:05– 3:00	Clinical vs. EEG – strengths and weaknesses for each seizure type	All – Nathan Fountain lead

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**3:00 – 3:15      BREAK**


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3:15 – 5:45	<b>Session III: Alternatives to diary seizure counting; devices – What is needed to operationalize counting by device</b>	
3:15 – 3:20	Lived Experience	Cody Stevens



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3:20 – 3:35	How close are we really? Levels and types of device available/inpatient/outpatient	Greg Worrell
3:35 – 3:50	Using non-EEG as a seizure counting outcome	Teresa Prego
3:50 – 4:05	Device Pragmatics – (e.g., device breakdown, lead dislodging failure to charge, refusal to wear, increased patient burden)	Dan Friedman
4:05 – 4:15	Device-specific and seizure-specific validity of seizure counting	Mark Cook
4:15 – 4:30	Devices / combo strategies for seizure types	Mark Lehmkuhle
4:30 – 4:45	Use case example	Jay Pathmanathan
4:45 – 5:00	FDA Reflections / Discussion	Michelle Campbell and Paul Lee / All
5:00 – 5:45	Open Discussion	
6:00 – 8:00	<b>RECEPTION</b>	

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## DAY 2 – Friday, April 25, 2025

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**7:30** **BREAKFAST**

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<b>8:30 – 12:20</b>	<b>Session IV: Alternatives to diary seizure counting that captures seizure disability; outcome assessments</b>	
8:30 – 8:35	Stage setting – Why do we need alternatives to seizure counting?	
8:35 – 8:40	Lived Experience	Anne Hendrix
8:40 – 9:20	What is not working for us now?	Stacy Thompson Stéphane Auvin, Anne Hendrix, Amit Ray
9:20 – 9:25	Reflections on participation of diary users	Rob Moss
9:25 – 10:00	FDA Reflections / Discussion	Michelle Campbell / All

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**10:00 – 10:15** **BREAK**

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10:15 – 11:00	Patient reported outcomes that capture seizure burden	Jackie French Stéphane Auvin Joyce Cramer
11:00 – 11:20	What would a valid scale look like? Use roadmap from PFDD draft guidance	Michelle Campbell
11:20 – 12:20	Open Discussion	

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**12:20 – 1:20** **LUNCH**

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**1:20 – 2:00** **Wrap Up**