



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

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
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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



10:10 – 10:25 BREAK

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	

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

12:30 – 1:30 LUNCH

1:30 – 3:00 Session II Continued

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

3:00 – 3:15 BREAK

3:15 – 5:45 Session III: Alternatives to diary seizure counting; devices – What is needed to operationalize counting by device

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	RECEPTION	
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DAY 2 – Friday, April 25, 2025

7:30

BREAKFAST

8:30 – 12:20

Session IV: Alternatives to diary seizure counting that captures seizure disability; outcome assessments

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

10:00 – 10:15

BREAK

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

12:20 – 1:20

LUNCH

1:20 – 2:00

Wrap Up