Presentation Time
September 6, 2026
14:00 – 15:00

ILAE EUROPE epilepsy congress

16th European Epilepsy Congress
5-9 September 2026 | Athens, Greece

THE DRAVET – DISEASE ASSOCIATED NEUROPSYCHIATRIC DISORDER (D-DAND) SCALE: AN EVALUATION TOOL INTEGRATED WITH ELECTROCLINICAL FOLLOW-UP

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PURPOSE

Dravet Syndrome (DS) is a Developmental and Epileptic Encephalopathy (DEE) characterized by seizure onset in the first year of life, followed by intellectual disability, behavioral problems, sleep and motor disturbances, and deficit in adaptive functioning. The Dravet–Disease Associated Neuropsychiatric Disorders (D-DAND) scale, currently undergoing final standardization, is a brief and easy-to-administer instrument that provides a comprehensive overview of the balance between a patient's strengths and difficulties while overcoming the floor effects observed with other instruments[1-2-3]. A correlation between the epileptological course and the clinical, adaptive, and behavioral profile of patients is plausible.

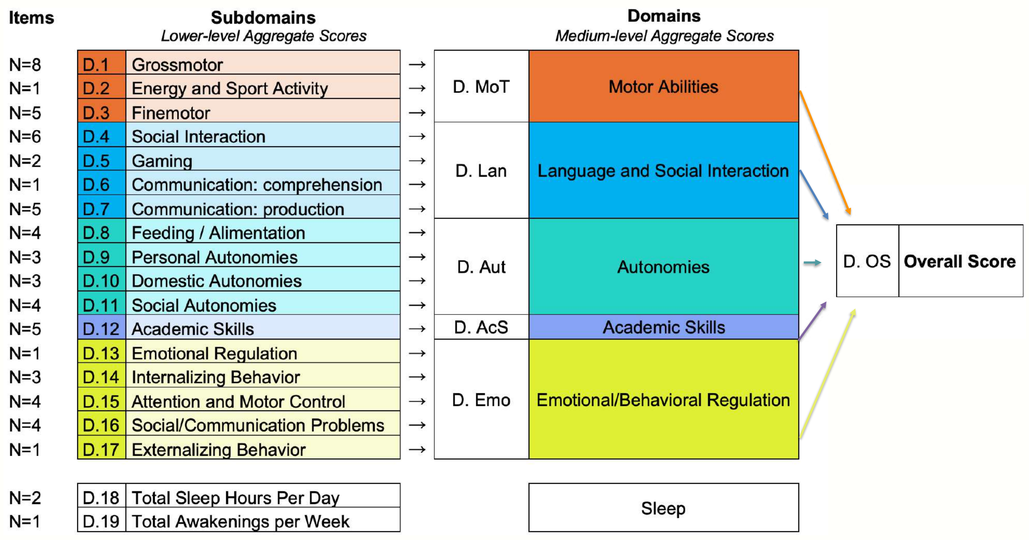


Figure 1. The D-DAND structure: items, subdomains, domains and overall score.

METHOD

To describe patient's clinical, adaptive, and behavioral profiles in detail, the D-DAND scale was administered twice, with a follow-up interval of 1 to 4-year. The interview, designed for patients aged 3 years and older, is structured into **six domains**: global motor function, language and social communication, personal autonomy, academic learning, behavioral and emotional problems, and sleep (Fig. 1). EEG findings and seizure history were assessed concurrently with the D-DAND scale.

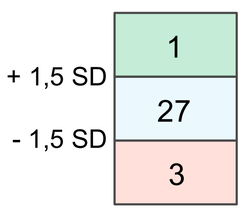
RESULTS

31 patients, **16M** **15F**

	T0	T1
age range	4 - 39 y	8 - 42 y
mean age; median age	15y 8m; 13y 9m	19y2m; 17y1m
	T0-T1 interval: from 1 to 4 y mean 3,3 y; median 3,5 y	

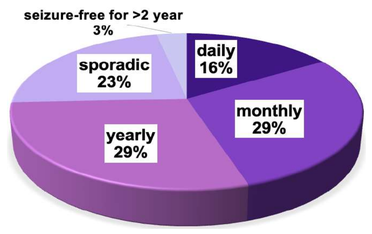
D-DAND scores and clinical data at T0

D-DAND overall Z-score

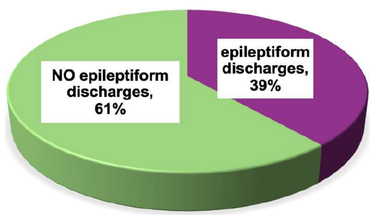


Overall D-DAND score showed a positive correlation with IQ/DQ (N = 25).

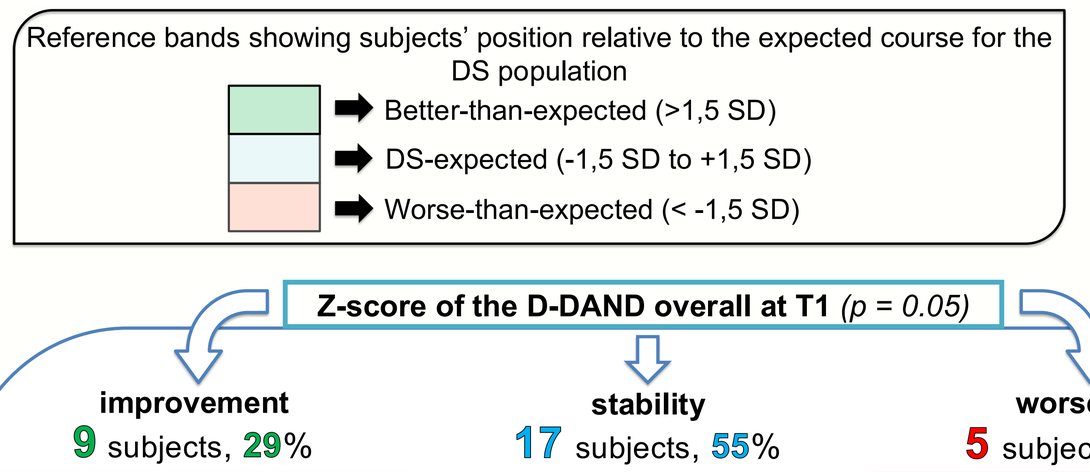
Seizures frequency



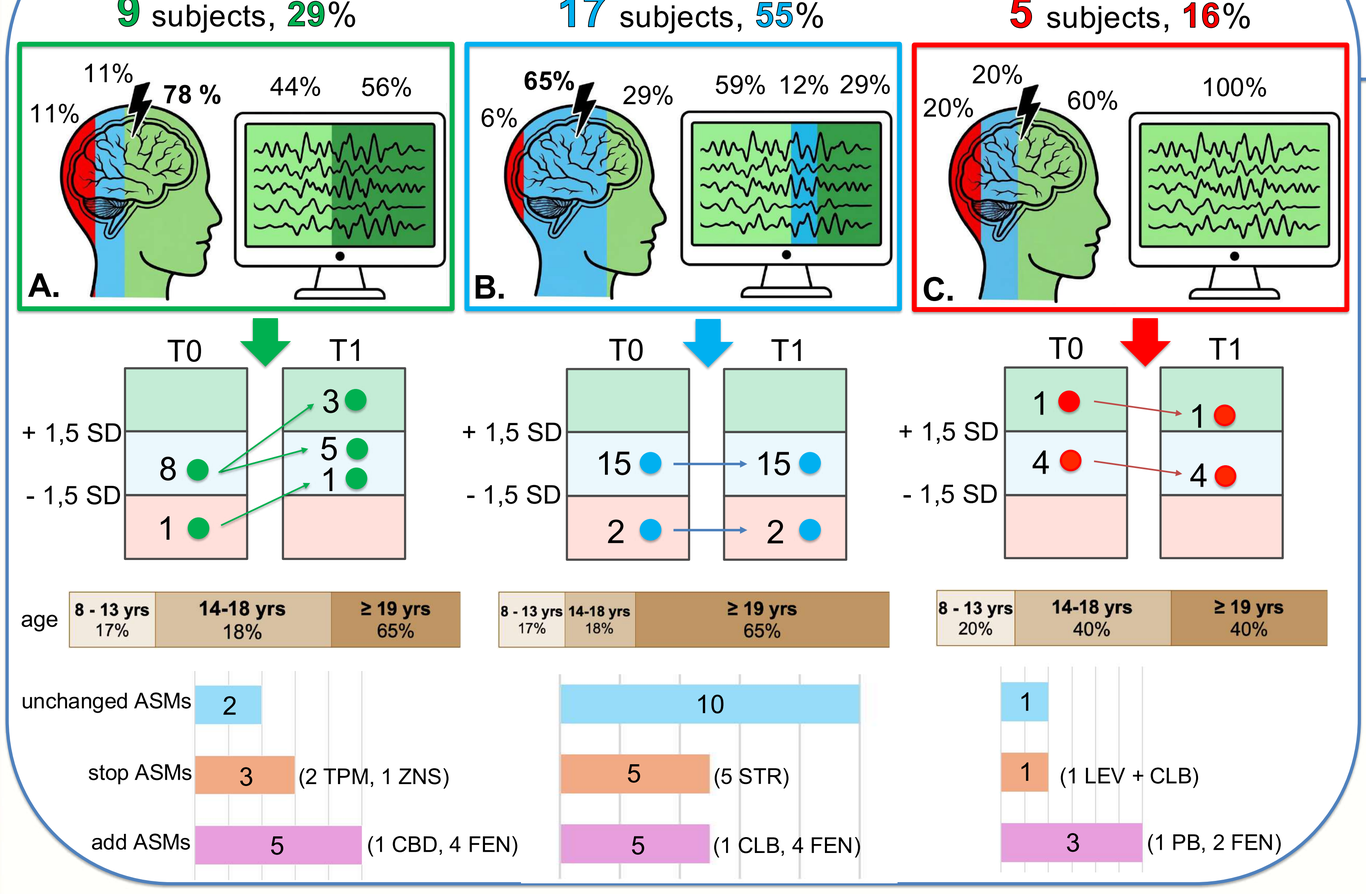
EEG



Pearson's correlation between IQ/DQ and DAND scores	*r*	two tail *p* = 0,01
Global motor function	0,439	N.S.
Language and social communication	0,429	N.S.
Personal autonomy	0,356	N.S.
Academic learning	0,362	N.S.
Behavioral and emotional problem	0,326	N.S.
OVERALL	0,484	0,01 *

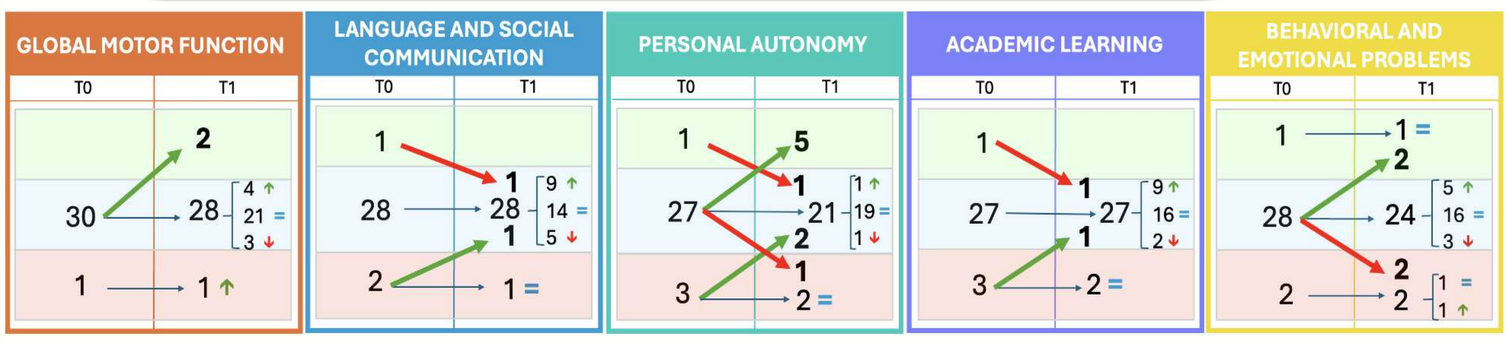


Z-score of the D-DAND overall at T1 *(p = 0.05)*



D-DAND overall T1 outcomes: improved (**A**), stable (**B**), or worsened (**C**). Color code for **seizures outcomes**: red = worsened, blue = stable, green = improved. Color code for **EEG outcomes**: red = worsened (none), blue = stable, light green = stable negative, dark green = improved. Improvement relative to the expected course was generally associated with better seizure and EEG outcomes. In stable patients, both seizures and EEG remained largely unchanged. In the worsened group, EEG remained negative in all cases, while seizures outcomes were heterogeneous, suggesting that overall worsening may be independent of epilepsy course[4]. No subjects transitioned into the "worse-than-expected" trajectory band (< -1,5 SD); only three subjects were in this band, both remained stable over time, and one improved. The incidence of unchanged conditions increased significantly in patients older than 19 years. Treatment changes (ASMs addition/discontinuation) were more frequent among improved subjects. Sixteen patients were already taking **Fenfluramine** at T0, and 10 started it between T0 and T1; of these, 4 moved to a higher band and 4 remained in the same band but showed improvement in specific domains.

Considering individual domains, 12/31 subjects (38.7%) showed a shift between trajectory bands in at least one domain. The five boxes below (Box 1) show subjects with significant changes in each domain, either leading to a **shift between trajectory bands** (red/green arrow) or **remaining within the same band** (thin arrow). These last subjects are further classified as showing significant improvement (↑), significant worsening (↓), or complete stability (=) within that band, despite no trajectory band shift. The most frequently modified domains were **autonomy and emotional–behavioral regulation.**



Box 1. Significant changes in each domain of D-DAND.

CONCLUSIONS

The **D-DAND** appears to be a useful instrument for characterizing the functioning of individuals with DS, enabling the **quantification of strengths and deficits that are not always captured by other standardized assessments.**

These results also suggest that the D-DAND is a sensitive instrument for **detecting significant longitudinal changes in the DS population**, capturing both gross atypical deviations and more subtle, yet still significant, changes relative to the expected trajectory.

With a larger study sample, it will be possible to assess any correlation between clinical course and therapeutic interventions, including pharmacological and abilitative ones.

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