SLC6A1-NDD PROSPECTIVE LONGITUDINAL NATURAL HISTORY STUDY (SPIRIT)

First published: 01/12/2025

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Study Ongoing

Administrative details

EU PAS number

EUPAS1000000861

Study ID

1000000861

DARWIN EU® study

No

Study countries

- Denmark
- European Union
- France
- Germany
- Italy
- Spain

United Kingdom

United States

Study status

Ongoing

Contact details

Study institution contact

UCB Cares UCBCares@ucb.com

Study contact

UCBCares@ucb.com

Primary lead investigator

UCB Cares

Primary lead investigator

Study timelines

Date when funding contract was signed

Actual: 27/01/2025

Study start date

Planned: 31/03/2026

Actual: 21/07/2026

Date of final study report

Planned: 05/09/2029

Sources of funding

- Pharmaceutical company and other private sector

More details on funding

UCB Biopharma SRL

Regulatory

Was the study required by a regulatory body?

No

Is the study required by a Risk Management Plan (RMP)?

Not applicable

Other study registration identification numbers and links

GTEP01

Methodological aspects

Study type

Study type list

Study topic:

Disease /health condition

Study type:

Non-interventional study

Scope of the study:

Disease epidemiology

Study drug and medical condition

Medical condition to be studied

SLC6A1 neurodevelopmental disorder

Data management

ENCePP Seal

The use of the ENCePP Seal has been discontinued since February 2025. The ENCePP Seal fields are retained in the display mode for transparency but are no longer maintained.

Use of a Common Data Model (CDM)

CDM mapping

No

Data quality specifications

Check conformance

Yes

Check completeness

Yes

Check stability

Yes

Check logical consistency

Yes

Data characterisation

Data characterisation conducted

Yes