

KIDSEP - Cohort of Children Monitored After First Episode of Acute Demyelination

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General

Identification

Detailed name Cohort of Children Monitored After First Episode of Acute Demyelination

Sign or acronym KIDSEP

CNIL registration number, number and date of CPP agreement, AFSSAPS (French Health Products Safety Agency) authorisation CNIL n°60060

General Aspects

Medical area Immunology
Neurology

Health determinants Genetic

Keywords multivariate analysis, Health episodes, child, epidemiology

Scientific investigator(s) (Contact)

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Unit E109/U802

Organization APHP

Collaborations

Funding

Funding status Private

Details	Association pour la Recherche sur la Sclérose en Plaques (ARSEP, France)
Governance of the database	
Sponsor(s) or organisation(s) responsible	APHP
Organisation status	Public
Additional contact	
Main features	
Type of database	
Type of database	Study databases
Study databases (details)	Cohort study
Database recruitment is carried out by an intermediary	A selection of health institutions and services
Database recruitment is carried out as part of an interventional study	No
Additional information regarding sample selection.	Prospective Inclusion cut-off date: 01/01/2010
Database objective	
Main objective	General objective: 1. To follow a national cohort of children from their first episode of acute demyelination and monitor them for over 10 years 2. To determine the clinical and radiological risk factors of recurrence (qualified by MS diagnosis) 3. To determine the progression towards disability and its risk factors 4. To participate in a genetic study regarding MS susceptibility 5. Pharmacovigilance (vaccines)
Inclusion criteria	Children who have experienced clinical symptoms of acute inflammatory demyelination (A1) between January 1990 and December 2003 before the age of 16.
Population type	
Age	Infant (28 days to 2 years) Early childhood (2 to 5 years) Childhood (6 to 13 years)

Adolescence (13 to 18 years)

Population covered Sick population

Gender Male
Woman

Geography area National

Detail of the geography area Multicentric cohort throughout France (11 centres)

Data collection

Dates

Date of first collection (YYYY or MM/YYYY) 01/1990

Date of last collection (YYYY or MM/YYYY) 01/2015

Size of the database

Size of the database (number of individuals) < 500 individuals

Details of the number of individuals 493

Data

Database activity Current data collection

Type of data collected Clinical data
Declarative data
Paraclinical data

Clinical data (detail) Direct physical measures
Medical registration

Declarative data (detail) Paper self-questionnaire

Paraclinical data (detail) Imaging

Presence of a biobank No

Health parameters studied Health event/morbidity
Health event/mortality

Procedures

Participant monitoring Yes

Details on monitoring of participants

Follow-up duration: 10 years

Links to administrative sources No

Promotion and access

Promotion

Link to the document <http://www.ncbi.nlm.nih.gov/pubmed/?term=KIDSEP>

Description List of publications in Pubmed

Access

Terms of data access (charter for data provision, format of data, availability delay) Data may not be used by academic teams Data may not be used by industrial teams

Access to aggregated data Access on specific project only

Access to individual data No access