

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