

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

Head :Mikaeloff Yann, E109/U802

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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)

Name of the director Mikaeloff

Surname Yann

Phone + 33 (0)6 64 31 20 97 ou +33 (0)1 45 21 31 32

Email yann.mikaeloff@bct.aphp.fr

Unit E109/U802

Organization APHP

### Collaborations

### Funding

Funding status Private

|  |  |
|--|--|
| Details  | Association pour la Recherche sur la Sclérose en Plaques (ARSEP, France)   |
| <b>Governance of the database</b>                                      |  |
| Sponsor(s) or organisation(s) responsible                              | APHP   |
| Organisation status  | Public   |
| <b>Additional contact</b>  |  |
| <b>Main features</b>   |  |
| <b>Type of database</b>  |  |
| 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   |
| <b>Database objective</b>  |  |
| 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.  |
| <b>Population type</b>   |  |
| Age  | Infant (28 days to 2 years)<br>Early childhood (2 to 5 years)<br>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