

CEPACS - Cohort of children with chromosomal structure abnormality

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General

Identification

Detailed name Cohort of children with chromosomal structure abnormality

Sign or acronym CEPACS

CNIL registration number, number and date of CPP agreement, AFSSAPS (French Health Products Safety Agency) authorisation Date de réception de l'avis favorable de la CNIL : 23/05/2007

General Aspects

Medical area Immunology

Health determinants Genetic

Keywords Health events, cytogenetic reorganization, motor cognitive and physical development, psychometric assessments, education, institutional caring

Scientific investigator(s) (Contact)

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Organization INSERM

Collaborations

Participation in projects, networks and consortia Yes

Others Participation in a cohort network: CEMARA - platform shared by 32 reference centers for rare diseases

Funding

Funding status Public

Details ----

Governance of the database

Sponsor(s) or organisation(s) responsible ASSISTANCE PUBLIQUE HOPITAUX DE PARIS

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

Database objective

Main objective The main objective of this cohort is clinical 1) Acquire information about motor, cognitive and physical development of patients carriers of micro-reorganizations depending on the type of anomaly declared 2) Define, through a longitudinal follow-up, the morbid complications (neurological progress or

degradation, epilepsy, incidence of common pathologies) and mortality rate of these patients 3) Specify psychological, medical and social caring parameters, education and socialization of these patients, medico-economic consequences. Secondary objective : Introduce, at the level of French population, the overall impact, the distribution by type of abnormality and by chromosomal region, the effects of environment variables such as parents age,...

Inclusion criteria

Chromosomal structure micro-reorganizations detected through molecular cytogenetic (Fish or CGH Array)

Population type

Age

Newborns (birth to 28 days)
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

French multi-center cohort (34 centers)

Data collection

Dates

Date of first collection (YYYY or MM/YYYY)

05/2007

Size of the database

Size of the database (number of individuals)

[1000-10 000] individuals

Details of the number of individuals

1000

Data

Database activity

Data collection completed

Type of data collected

Clinical data
Declarative data
Paraclinical data
Biological data

Clinical data (detail)	Direct physical measures Medical registration
Details of collected clinical data	Clinical examination at inclusion and during the follow-up. Information collected during the clinical examination : indirect collection through parents, most of the time (mentally disabled patients)
Declarative data (detail)	Face to face interview
Details of collected declarative data	Clinical examination at inclusion and during the follow-up. Information collected during the clinical examination : indirect collection through parents, most of the time (mentally disabled patients)
Paraclinical data (detail)	Imaging: different examinations can be collected depending on clinical constraints. No examination is collected without being justified by medical follow-up good practice.
Biological data (detail)	Samples: karyotype and DNA collected with diagnostic purposes, in the context of an etiologic checkup. The results of this examination are a prerequisite for the inclusion in the cohort
Presence of a biobank	Yes
Contents of biobank	DNA
Details of biobank content	DNA bank
Health parameters studied	Health event/morbidity Health event/mortality
Procedures	
Data collection method	Interviews: manually entered paper questionnaire Clinical examinations: hand-written step Biological examinations: hand-written step
Participant monitoring	Yes
Details on monitoring of participants	Undetermined period
Links to administrative sources	Yes
Linked administrative sources (detail)	CépiDC
Promotion and access	

Promotion

Access

Dedicated website

<https://cemara.org>

Terms of data access (charter for data provision, format of data, availability delay)

Possible data utilization by academic teams? Yes.
Contractual access conditions.
Data utilization available for industry sectors? Non

Access to aggregated data

Access on specific project only

Access to individual data

Access on specific project only