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