CEPACS - Cohort of children with chromosomal structure abnormality

Head :Verloes Alain, INSERM U676 (PHYSIOPATHOLOGIE, CONSEQUENCES FONCTIONNELLES ET NEUROPROTECTION DES ATTEINTES DU CERVEAU EN DEVELOPPEMENT) DEPARTEMENT DE GENETIQUE

Last update : 02/28/2014 | Version : 1 | ID : 60091

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)	
Name of the director	Verloes
Surname	Alain
Address	75019 PARIS
Phone	+ 33 (0)1 40 03 53 41
Email	alain.verloes@rdb.aphp.fr
Unit	INSERM U676 (PHYSIOPATHOLOGIE, CONSEQUENCES FONCTIONNELLES ET NEUROPROTECTION DES ATTEINTES DU CERVEAU EN DEVELOPPEMENT) DEPARTEMENT DE GENETIQUE

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

Details of collected clinical data 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 interviewDetails of collected declarative dataClinical 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)Pataclinical 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 heckup. The results of this examination are a prerequisite for the inclusion in the cohortPresence of a biobankPNADetails of biobank contentDNAHealth parameters studiedHealth event/morbidty
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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 Undetermined period participants
Links to administrative sources Yes
Linked administrative sources CépiDC (detail)

Promotion and access

PromotionAccessDedicated websitehttps://cemara.orgTerms 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? NonAccess to aggregated dataAccess on specific project onlyAccess to individual dataAccess on specific project only