Cohort CP - Longitudinal Study of a Children Population With Bilateral Severe Cerebral Palsy: Incidence and Evolution of Orthopaedic Complications and Pain Related With These Complications.

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General

Identification

Detailed name	Longitudinal Study of a Children Population With Bilateral Severe Cerebral Palsy: Incidence and Evolution of Orthopaedic Complications and Pain Related With These Complications.
Sign or acronym	Cohort CP
CNIL registration number, number and date of CPP agreement, AFSSAPS (French Health Products Safety Agency) authorisation	CNIL : 910232

General Aspects

Medical area	Disability/handicap Neurology Pediatrics Physical medicine and rehabilitation Radiology and medical imaging
Health determinants	Lifestyle and behavior Social and psychosocial factors
Keywords	pain ; child ;cohort ; orthopaedic complications ; epidemiology ; cerebral palsy

Scientific investigator(s) (Contact)

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Unit	Service « L'Escale », Rééducation Fonctionnelle Infantile
Organization	Groupement Hospitalier Est, Hospices Civils de Lyon

Collaborations

Participation in projects, networks and consortia	Yes
Details	Investigator annual meeting during the SFERHE study days (Société Francophone d'Etude et de Recherche sur les Handicaps de l'Enfance)

Funding

Funding status	Mixed
Details	Programme Hospitalier de Recherche Clinique (PHRC) ; La Fondation Motrice ; TFWA Care; Association Lyonnaise de Logistique Post-Hospitalière (ALLP) ; SFERHE Funding (Société Francophone d'Etude et de Recherche sur les Handicaps de l'Enfance)

Governance of the database

Sponsor(s) or organisation(s) responsible	Groupement Hospitalier Est, Hospices Civils de Lyon
Organisation status	Public
Presence of scientific or steering committees	No

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	No

study	
Additional information regarding sample selection.	Patients are enrolled among University-affiliated Hospital (CHU), General Hospital (CH), medicoeducational institutes (IME), Institutes for motor skills development (IEM), Center for motor skills development (CEM), Specialized home education and healthcare service (SESSAD), Centres for early medicosocial action (CAMPS). To Avoid selection bias, investigator was asked to enrolled all elligible patient of their services. Enrollement is currently on-going.

Database objective

Main objective	The primary objective is to establish the incidence of orthopaedic complications (scoliosis and hip joint) depending on patients' age. Secondary objectives are to describe the sequences over time of these complications and the related pain, to explore the impact of nutrition, surgery, asymmetric postures and environmental factors, and to describe the medical and rehabilitative follow-up of these patients.
Inclusion criteria	- Children aged from 2 to 10 years at inclusion, - with bilateral cerebral palsy (Brain injury or cerebral abnormalities ocurred before 2 years of age), - Grade IV or V of the GMFCS. - nonprogressive disease

Population type

Age	Early childhood (2 to 5 years) Childhood (6 to 13 years) Adolescence (13 to 18 years) Adulthood (19 to 24 years)
Population covered	Sick population
Pathology	G80 - Cerebral palsy
Gender	Male Woman
Geography area	National
Detail of the geography area	France and DOMs (Réunion Island, Polynesia & Martinique)

Data collection

Dates	
Date of first collection (YYYY or MM/YYYY)	09/2009
Date of last collection (YYYY or MM/YYYY)	on-going

Size of the database	
Size of the database (number of individuals)	< 500 individuals
Details of the number of individuals	311 (07/02/2017)

Data	
Database activity	Current data collection
Type of data collected	Clinical data Paraclinical data
Clinical data (detail)	Direct physical measures Medical registration
Paraclinical data (detail)	Radiological exam (hips & spine radiological measurement)
Presence of a biobank	No
Health parameters studied	Health event/morbidity Health event/mortality

Procedures	
Data collection method	Data are collected in Case Reported Form (CRF) by study investigators during annual patient visits. Those visits are included in the patient usual follow-up. Collected data are based on parents questionning, patient clinical exam, child radiographies and medical record if applicable (medical histroy, clinical and paraclinical data...)
Participant monitoring	Yes
Details on monitoring of participants	Each patient follow-up last 10 years with 1 visit / year. Before each annual visit, a new CRF is send to study investigators. The same CRF model is used for the 10 visits)
Links to administrative sources	No

Promotion and access

Promotion

Link to the document	http://www.em-consulte.com/en/article/855582
Description	Physiopathological hypothesis of hip excentration in cerebral palsy, from a field experience
Link to the document	https://www.ncbi.nlm.nih.gov/pubmed/24120244
Description	Rehabilitation of 190 non-ambulatory children with cerebral palsy in structures of care or in liberal sector.

Access

Terms of data access (charter for data provision, format of data, availability delay)	- Approach to access the completed database : not yet discussed - Approach to access a part of the results: 2 published articles , 1 submitted article , 1 article currently being drafted
Access to aggregated data	Access on specific project only
Access to individual data	Access on specific project only