- Ile de la Réunion Congenital anomalies register

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General

Identification

Detailed name	Ile de la Réunion Congenital anomalies register
CNIL registration number, number and date of CPP agreement, AFSSAPS (French Health Products Safety Agency) authorisation	autorisation n°909410

General Aspects

Medical area	Rare diseases
Pathology (details)	Teratovigilance, Toxicovigilance
Health determinants	Addictions Genetic Iatrogenic Intoxication Nutrition Occupation Pollution Social and psychosocial factors
Keywords	congenital abnormalities, prenatal diagnosis, alert, toxic risk factors to reproduction, teratogens, genetics, database, epidemiology, surveillance

Scientific investigator(s) (Contact)

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Organization	CHR Site de St

Collaborations

Funding

Funding status	Public
Details	Institut de veille sanitaire - InVSInstitut national de la santé et de la recherche médicale - INSERMAgence régionale de santé - ARS

Governance of the database

Sponsor(s) or organisation(s) responsible	CHU Réunion- ARS
Organisation status	Public
Organisation status	
Sponsor(s) or organisation(s) responsible	Inserm
Organisation status	Public
Sponsor(s) or organisation(s) responsible	InVS
Organisation status	Private
Presence of scientific or steering committees	Yes

Additional contact

Main features

Type of database

Type of database	Morbidity registers
Additional information regarding sample selection.	Method for selecting subjects having the required inclusion criteria. Several sources are used to identify cases in which mothers live on Reunion Island and for which the malformation diagnosis is made either before the birth or after - up until the end of the infant's first year of life: - Public and private maternity wards throughout the island - Neonatology and multidisciplinary intensive care

	departments - Departments for surgery in children and pediatric cardiology - Neurosurgery and neuroradiology departments - Hospital Medical Information Departments - Cytogenetics laboratory and medical genetics departments - Fetopathology laboratory - Multidisciplinary Centers for Prenatal Diagnosis

Database objective

Main objective	1. Carry out epidemiological surveillance of congenital abnormalities in the population of Reunion Island (determination of prevalence and distribution) and identification of malformation risk factors (genetic, environmental, related to drugs or toxins); with the purpose of sounding the alert when any environmental teratogenic agents become evident (e.g. drug, pesticide exposure, industrial accident) at local, national and international level. Should clusters of malformations be detected (surveillance-alert of an increase in prevalence over time of a given malformation), checks must be made regarding recording bias before conducting further investigations. Then specific risk factors will be sought. 2. Evaluate the impact of public health initiatives in the population: - Evaluation of prenatal screening of malformations is a fundamental objective for the registry, with participation in the field of perinatal medicine and local obstetric practices - Implementation and evaluation of prevention initiatives are also important, such as the primary prevention of neural tube closing defects via folic acid supplements before conception. 2. Identification of possible new syndromes and supply of new information for genetic counseling of families. e-transmission method, genetic heterogeneity, genetic susceptibility factor.
Inclusion criteria	The Registry lists cases of malformation and chromosomal abnormality among living births, still births (from 22 weeks of amenorrhea or more), which are diagnosed within or at one year, as well as therapeutic abortions irrespective of the gestational age. The following are included in the registry: Congenital malformations diagnosed before or after

	the birth - up until the end of the infant's first year of life.

Population type

Age	Newborns (birth to 28 days) Infant (28 days to 2 years)
Population covered	Sick population
Gender	Male Woman
Geography area	Regional
French regions covered by the database	La Réunion
Detail of the geography area	Reunion department

Data collection

Dates

Date of first collection (YYYY or MM/YYYY)	2002

Size of the database

Size of the database (number of individuals)	[1000-10 000[individuals
Details of the number of individuals	2002-2009: 3046 cas (source EUROCAT)2009 : 419 cas (source EUROCAT)

Data

Database activity	Current data collection
Type of data collected	Clinical data Administrative data
Clinical data (detail)	Direct physical measures
Administrative data (detail)	Identification data:- Date of birth- Place of birth- Postcode (place of residence)Sociodemographic data:- Sex of child- Mother's age- Geographical origin of parents- Parents' profession
Presence of a biobank	No
Health parameters studied	Health event/morbidity

	Health event/mortality
Procedures	
Data collection method	Active collection: survey takers go to the departments and record in their databases all of the information contained in the medical records concerning congenital malformations and their determining factors
Classifications used	ICD10 for malformations and diseases
Participant monitoring	Yes
Details on monitoring of participants	Vital status
Links to administrative sources	Yes
Linked administrative sources (detail)	Request made by health institutions to medical information departments.
Promotion and access	
Promotion	
Access	
Presence of document that lists variables and coding procedures	Yes
Terms of data access (charter for data provision, format of data, availability delay)	Publications and reports. Access to overall data: EUROCAT website: http://www.eurocat-network.eu/ Access to individual (anonymized) data possible by request.
Access to aggregated data	Free access
Access to individual data	Access on specific project only