

REMERA - Rhône Alpes birth defects registry

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General	
Identification	
Detailed name	Rhône Alpes birth defects registry
Sign or acronym	REMERA
CNIL registration number, number and date of CPP agreement, AFSSAPS (French Health Products Safety Agency) authorisation	CNIL N°910397
General Aspects	
Medical area	Disability/handicap Gynecology/ obstetrics
Health determinants	Addictions Genetic Iatrogenic Intoxication Lifestyle and behavior Medicine Nutrition Occupation Pollution Social and psychosocial factors
Keywords	prevalence of congenital malformations, reprotoxic risk factors, antenatal screening, eugenic abortions, perinatality, database on malformations, epidemiology, follow-up, alert, teratogens, genetics
Scientific investigator(s) (Contact)	
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Organization	REMER A et CHU DE

Collaborations

Funding

Funding status	Public
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Details	InVS, Conseil Régional Rhône Alpes, Inserm, Afssaps, Registre qualifié de 2009 à 2011
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Governance of the database

Sponsor(s) or organisation(s) responsible	Registre des Malformations en Rhône Alpes
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Organisation status	Both
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Additional contact

Main features

Type of database

Type of database	Morbidity registers
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Database objective

Main objective	Objectives in terms of public health: 1) Evaluation of the importance of the change in malformations (incidence, factors, appearance of a new malformation or of a new malformation symptom, space-time variations of these incidences) 2) Evaluation of the actions in public health: measure the impact of the actions implemented, especially perinatal screening and also the primary prevention initiatives on the prevalence of malformations and propose orientations for the development of health programs. 3) Alert in the case where a link with a teratogen, whether or not known, is suspected In terms of research: 1) Highlight the factors of risk of malformation 2) Study their interactions with susceptibilities of a genetic nature
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Inclusion criteria	The following are included in the registry: Congenital malformations diagnosed antenatally or
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postnatally until the end of the 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	Departmental
French regions covered by the database	Auvergne Rhône-Alpes
Detail of the geography area	Département of Rhône, Isère, Savoie, and Loire
Data collection	
Dates	
Date of first collection (YYYY or MM/YYYY)	01/1973
Size of the database	
Size of the database (number of individuals)	Greater than 20 000 individuals
Details of the number of individuals	61 000 (in 2012)
Data	
Database activity	Current data collection
Type of data collected	Clinical data Declarative data Paraclinical data Biological data Administrative data
Clinical data (detail)	Direct physical measures
Declarative data (detail)	Phone interview
Paraclinical data (detail)	Height, weight, BP of mother ; height, weight, head circumference, crown-rump length of the child/fetus

Biological data (detail)	triple test, karyotype, glycemia
Administrative data (detail)	Identification data (Name, first name, birthday, location, sex)
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 dossiers concerning congenital malformations and their determinants
Participant monitoring	No
Links to administrative sources	No
Promotion and access	
Promotion	
Access	
Terms of data access (charter for data provision, format of data, availability delay)	An annual activity report Access to the data (depersonalized) is possible, on request
Access to aggregated data	Access on specific project only
Access to individual data	Access on specific project only