

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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| Unit | REMERA9 Quai Jean Moulin690001 LYON |
| Organization | REMERA et CHU DE |

Collaborations

Funding

Funding status Public

Details InVS, Conseil Régional Rhône Alpes, Inserm, Afssaps, Registre qualifié de 2009 à 2011

Governance of the database

Sponsor(s) or organisation(s) responsible Registre des Malformations en Rhône Alpes

Organisation status Both

Additional contact

Main features

Type of database

Type of database Morbidity registers

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

Inclusion criteria The following are included in the registry:
Congenital malformations diagnosed antenatally or

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

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|------------------------------|---|
| 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

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| 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

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|---|--|
| 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 |