

- Registry of Congenital Malformations in Brittany (qualified registry 2013-2015)

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General

Identification

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| Detailed name | Registry of Congenital Malformations in Brittany (qualified registry 2013-2015) |
| CNIL registration number, number and date of CPP agreement, AFSSAPS (French Health Products Safety Agency) authorisation | CNIL n°910138 du 11/8 /2010 ; CCTIRS n° 10.145 du 11/3/2010 |

General Aspects

| | |
|---------------------|---|
| Medical area | Disability/handicap |
| Health determinants | Geography Lifestyle and behavior |
| Keywords | heart defects, diaphragmatic hernia, hypospadia, Spina bifida |

Scientific investigator(s) (Contact)

| | |
|----------------------|--|
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| Unit | U1085 Institut de recherche, santé, environnement et travail. |
| Organization | CHU de |

Collaborations

Funding

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|--|--|
| Funding status | Public |
| Details | - Institut de veille sanitaire - InVS- Agence régionale de santé - ARS- Conseil général |
| Governance of the database | |
| Sponsor(s) or organisation(s) responsible | CHU de Rennes |
| Organisation status | Public |
| Additional contact | |
| Main features | |
| Type of database | |
| Type of database | Morbidity registers |
| Additional information regarding sample selection. | Cases referred by practitioners and researcher completeness checks. |
| Database objective | |
| Main objective | To carry out a health watch, monitor prevalency according to time and space and identify tetrogenic factors. To assess medical treatment requirements. To study environmental factors and begin a geospatial analyses for certain malformations in connection with surrounding activities. |
| Inclusion criteria | - Live births or foetal deaths with gestational age at \geq 22 weeks and pregnancy terminations for medical reasons - born on or after 1st September 2010 - with congenital anomaly (EUROCAT criteria) diagnosed during the first year of life - mother living in Brittany. |
| 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 | Bretagne |

database

| | |
|------------------------------|--|
| Detail of the geography area | Brittany: Ille et Vilaine and Côtes d'Armor (106 registered centres) |
|------------------------------|--|

Data collection

Dates

| | |
|--|---------|
| Date of first collection (YYYY or MM/YYYY) | 09/2010 |
|--|---------|

| | |
|---|---------|
| Date of last collection (YYYY or MM/YYYY) | 10/2014 |
|---|---------|

Size of the database

| | |
|--|------------------------|
| Size of the database (number of individuals) | [500-1000[individuals |
|--|------------------------|

| | |
|--------------------------------------|---------------|
| Details of the number of individuals | 700 /an /year |
|--------------------------------------|---------------|

Data

| | |
|-------------------|-------------------------|
| Database activity | Current data collection |
|-------------------|-------------------------|

| | |
|------------------------|-----------------------------------|
| Type of data collected | Clinical data Declarative data |
|------------------------|-----------------------------------|

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|------------------------|----------------------|
| Clinical data (detail) | Medical registration |
|------------------------|----------------------|

| | |
|---------------------------|-----------------|
| Declarative data (detail) | Phone interview |
|---------------------------|-----------------|

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|-----------------------|----|
| Presence of a biobank | No |
|-----------------------|----|

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|---------------------------|------------------------|
| Health parameters studied | Health event/morbidity |
|---------------------------|------------------------|

Procedures

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|------------------------|-----|
| Data collection method | --- |
|------------------------|-----|

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|------------------------|-----|
| Participant monitoring | Yes |
|------------------------|-----|

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|---------------------------------|----|
| Links to administrative sources | No |
|---------------------------------|----|

Promotion and access

Promotion

| | |
|----------------------|---|
| Link to the document | http://www.cclinouest.com/JOSE/Page_2012/Rouget_registre_phrc_JOSE3.pdf |
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Link to the document <http://tinyurl.com/HAL-RMCB>

Description Liste des publications dans HAL

Link to the document <http://tinyurl.com/PUBMED-RMCB>

Description Liste des publications dans Pubmed

Access

Terms of data access (charter for data provision, format of data, availability delay) Contact the scientist in charge

Access to aggregated data Access on specific project only

Access to individual data Access on specific project only