

CEMC-Auvergne - Registry of Congenital Malformations in Auvergne (Certified Registry 2012-2015)

Responsable(s) :Perthus Isabelle

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Général

Identification

Nom détaillé Registry of Congenital Malformations in Auvergne (Certified Registry 2012-2015)

Sigle ou acronyme CEMC-Auvergne

Numéro d'enregistrement (ID-RCB ou EUDRACT, CNIL, CPP, etc.) 1387396

Thématiques générales

Domaine médical Disability/handicap
Pediatrics
Rare diseases

Déterminants de santé Addictions
Genetic
Iatrogenic
Lifestyle and behavior
Medicine

Mots-clés prenatal diagnosis

Responsable(s) scientifique(s)

Nom du responsable Perthus

Prénom Isabelle

Adresse Service de génétique, CHU Estaing, 1 place Lucie Aubrac 63 003 cédex 1

Téléphone + 33 (0)4 73 34 19 32

Email iperthus@chu-clermontferrand.fr

Organisme CEMC-Auvergne

Collaborations

Financements

Financements	Mixed
Précisions	Regional Health Agency - ARS - French Institute for Public Health Surveillance - InVS -French National Institute of Health and Medical Research - INSERM, private donations.
Gouvernance de la base de données	
Organisation(s) responsable(s) ou promoteur	CHU de Clermont-Ferrand
Statut de l'organisation	Secteur Public
Contact(s) supplémentaire(s)	
Caractéristiques	
Type de base de données	
Type de base de données	Morbidity registers
Informations complémentaires concernant la constitution de l'échantillon	Selection of subjects having the required inclusion criteria:- Public and private maternity wards in the Auvergne region- Multidisciplinary center for prenatal diagnosis- Medical and surgical pediatric departments- Cardiology departments- Maxillo-facial surgery- Pediatric urology- Public and private cytogenetics laboratories- Anatomopathology laboratory- Mother and child protection centers (PMIs)- Medical information departments (DIMs)
Objectif de la base de données	
Objectif principal	The registry's primary objective is to conduct epidemiological surveillance of congenital malformations in Auvergne, with a role of sounding the alert when any environmental teratogenic agents become evident. With the development of prevention measures - particularly in the field of prenatal diagnosis - this surveillance-alert mission has gradually been extended to include an essential role in evaluating the impact of public health policies with regards to perinatal care on the population. The registry also helps to improve knowledge in the field of malformations by collaborating on studies with specialist clinical departments (particularly genetic and foetal medicine departments) and by being involved in the Multidisciplinary Center for Prenatal Diagnosis

in Clermont-Ferrand (the registry's data provides food for thought from obstetricians on the meaning and action to take when certain malformations are observed during prenatal diagnosis). Lastly, the registry's data informs healthcare stakeholders and the public authorities about congenital malformations and chromosomal abnormalities.

Critères d'inclusion

All malformed children are listed, whether stillborn or a live birth after a pregnancy of at least 22 weeks of amenorrhoea, or in the event of therapeutic abortion due to foetal malformation, regardless of term. For children who are born alive, the malformation diagnosis must have been made before the end of their first year of life (infants may be recorded up to 12 months after their birth). All types of malformation are included, whether these concern isolated or polymalformative syndromes, whether or not identified, with normal or abnormal karyotype. The only types to be excluded are inborn metabolic errors and minor malformations or deformations (snapping hips without real dislocation, deformed feet, small superficial naevi or angiomas less than 4cm², inguinal hernia, umbilical hernia not requiring surgery, isolated persistent ductus arteriosus in premature infants weighing less than 2.5kg, hypertrophic pyloric stenosis, single umbilical artery, uni- or bilateral ectopic testis).

Type de population

Age	Newborns (birth to 28 days) Infant (28 days to 2 years)
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Population concernée	Sick population
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Sexe	Male Woman
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Champ géographique	Regional
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Régions concernées par la base de données	Auvergne Rhône-Alpes
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Détail du champ géographique	Auvergne
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Collecte

Dates

Année du premier recueil 1983

Taille de la base de données

Taille de la base de données (en nombre d'individus) [10 000-20 000[individuals

Détail du nombre d'individus 10 145 patients (1983-2011)

Données

Activité de la base Current data collection

Type de données recueillies
Clinical data
Paraclinical data
Biological data
Administrative data

Données cliniques, précisions Direct physical measures

Données paracliniques, précisions MRI, scan, radiographies, ultrasounds (prenatal, foetal echocardiography, in post-natal stages: urinary tracts, cardio, etc.).

Données biologiques, précisions cytogenetic examinations, maternal serum markers.

Données administratives, précisions Identification data.

Existence d'une bibliothèque No

Paramètres de santé étudiés
Health event/morbidity
Health event/mortality

Modalités

Mode de recueil des données primarily active +/- passive.

Nomenclatures employées ICD 10, ATC.

Suivi des participants Yes

Détail du suivi
Vital status: The vital status is reported systematically when each case is being registered. The following are distinguished: - children who are alive when the report is made to the registry - therapeutic abortions before 22 weeks of amenorrhoea- therapeutic abortions after 22 weeks of amenorrhoea- fetal deaths in utero- infants who have died (in the first 8 days of life, between 8 and 28 days or after 28 days)

Appariement avec des sources administratives	No
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Valorisation et accès

Valorisation et accès

Lien vers le document	http://tinyurl.com/PUBMED-CEMC
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Description	Liste des publications dans Pubmed
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Lien vers le document	http://tinyurl.com/HAL-CEMC
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Description	Liste des publications dans HAL
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Accès

Charte d'accès aux données (convention de mise à disposition, format de données et délais de mise à disposition)	By request to the scientist in charge.
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Accès aux données agrégées	Access on specific project only
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Accès aux données individuelles	Access on specific project only
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