

AVCNN - French Cohort on Neonatal Cerebral Artery Infarction

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General

Identification

Detailed name French Cohort on Neonatal Cerebral Artery Infarction

Sign or acronym AVCNN

CNIL registration number, number and date of CPP agreement, AFSSAPS (French Health Products Safety Agency) authorisation Accord CNIL : 24/03/2004

General Aspects

Medical area Physical medicine and rehabilitation

Health determinants Genetic

Keywords History, miscarriage, primiparity, first gestation, twin pregnancy, premature rupture of membranes, caesarean section, foetal distress, monitoring, medical care, reeducation and rehabilitation, information

Scientific investigator(s) (Contact)

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Collaborations

Participation in projects, networks and consortia Yes

Funding

Funding status Mixed

Details Public: Inserm, Ministère de la Santé et des Solidarités, CHU de SAINT-ETIENNE, Privé: Fondation Motrice, Association des paralysés de France, Fondation Garches

Governance of the database

Sponsor(s) or organisation(s) responsible CHU de Saint-Etienne

Organisation status Public

Additional contact

Main features

Type of database

Type of database Study databases

Study databases (details) Longitudinal study (except cohorts)

Database recruitment is carried out by an intermediary A selection of health institutions and services

Database recruitment is carried out as part of an interventional study No

Additional information regarding sample selection. Prospective Inclusion cut-off date: 01/10/2006
Other bodies active in creating this cohort: CHU, CHG

Database objective

Main objective General objective: to determine the clinical and biological obstetric-neonatal profile for full-term newborns presenting symptomatic arterial ischaemic stroke. Secondary objectives: - to determine the mechanisms of infarction from obstetric history, laboratory tests and imaging. - To monitor motor, cognitive and epileptic outcomes in children as well as their autonomy and quality of life until primary school.

Inclusion criteria All participating newborns hospitalised by neonatal and paediatric neurology services. Full-term newborns presenting perinatal arterial ischaemic

stroke were included i.e.: - presenting neurological symptoms (convulsions, malaise, hypotonia, impaired vigilance, asymmetric tone or motor skills) in the first 28 days of life; - Brain imaging (by CT or MRI scan) showing appearance of ischaemic-like lesions in an arterial location; - parents or those with parental authority who gave their consent after explanation of the protocol aims and modalities by the local investigating party and who received an explanatory document. Exclusion criteria: - premature births; - asymptomatic neonates i.e. systematic discovery of an immediate pre- or post-natal image abnormality or children presenting with a posteriori cerebral palsy; - children with diffuse hypoxic-ischaemic lesions i.e more than three affected arterial territories or venous infarction; - where clinical and biological follow-up is impossible; - parental refusal to be included in the study or refusal to sign molecular biology consent form.

Population type

Age	Newborns (birth to 28 days) Childhood (6 to 13 years) Adolescence (13 to 18 years)
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Population covered	Sick population
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Gender	Male Woman
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Geography area	National
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Detail of the geography area	Multicentric cohort throughout France (39 centres) Geographical area covered: 39 neonatal and paediatric neurology services throughout the metropolitan territory: ANNEMASSE, AULNAY SOUS BOIS, AUXERRE, AVIGNON, BAYONNE, BEAUVAIS, BESANÇON, BONDY, BREST, CAHORS, CARCASSONE, CHALON SUR SAÔNE, CLAMART, CLERMONT-FERRAND, CREIL, CRÉTEIL, EVRY, FONTAINEBLEAU, GRENOBLE, LE KREMLIN-BICÊTRE, LILLE, LIMOGES, LYON, MARSEILLES, MONTPELLIER, NANTES, ORSAY), PARIS (ROBERT DEBRÉ, SAINT-VINCENT DE PAUL) PÉRIGUEUX, ROUEN, SAINT-DENIS, SAINT-ETIENNE, TOULOUSE, TOURS, VANNES, VERSAILLES, VILLEFRANCHE SUR SÂONE AND VILLENEUVE SAINT-GEORGES.
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Data collection

Dates

Date of first collection (YYYY or MM/YYYY) 11/2003

Size of the database

Size of the database (number of individuals) < 500 individuals

Details of the number of individuals 100

Data

Database activity Data collection completed

Type of data collected
Clinical data
Declarative data
Paraclinical data
Biological data

Clinical data (detail) Direct physical measures
Medical registration

Declarative data (detail) Paper self-questionnaire
Face to face interview

Paraclinical data (detail) Imaging

Biological data (detail) Thrombophilia research for mother and child

Presence of a biobank No

Health parameters studied Quality of life/health perception

Procedures

Data collection method
Self-administered questionnaire: from a paper questionnaire
Interview: from a paper questionnaire
Clinical examination: manual input and double data entry
Biological analysis: manual input and double data entry

Participant monitoring Yes

Details on monitoring of participants
Clinical examination at birth, at one year, two years and seven years old. Self-administered questionnaire at the age of three and half and seven years old. Neuropsychological and speech therapy evaluation at seven years old.

Links to administrative sources No

Promotion and access

Promotion

Link to the document <http://tinyurl.com/Hal-Publis-AVCnn>

Description List of publications in HAL

Link to the document [http://www.ncbi.nlm.nih.gov/pubmed/?term=AVCNN+OR+19541515\[uid\]](http://www.ncbi.nlm.nih.gov/pubmed/?term=AVCNN+OR+19541515[uid])

Description List of publications in Pubmed

Access

Terms of data access (charter for data provision, format of data, availability delay) Data may be used by academic teams To be decided if data may be used by industrial teams.

Access to aggregated data Access on specific project only

Access to individual data Access on specific project only