AVCNN - French Cohort on Neonatal Cerebral Artery Infarction

Head :Chabrier Stéphane, INSERM, CIE3, F-42055 SAINT-ETIENNE

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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)

Name of the director	Chabrier
Surname	Stéphane
Address	42055 SAINT-ETIENNE
Phone	+ 33 (0)4 77 82 87 29
Email	stephane.chabrier@chu-st-etienne.fr
Unit	INSERM, CIE3, F-42055 SAINT-ETIENNE

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 aposteriori 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)
Population covered	Sick population
Gender	Male Woman
Geography area	National
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.
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]
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