

- Autism-psl

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Last update : 08/01/2014 | Version : 1 | ID : 5169

General	
Identification	
Detailed name	Autism-psl
CNIL registration number, number and date of CPP agreement, AFSSAPS (French Health Products Safety Agency) authorisation	CPP: 26/10/2012, CPP/74-12 - ID RCB : 2012-A00936-37 - autorisation ansm : B121009-40
General Aspects	
Medical area	Psychology and psychiatry
Health determinants	Genetic
Others (details)	Autism
Keywords	Autism genetics
Scientific investigator(s) (Contact)	
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Unit	CRICM - UPMC/Inserm UMR_S975/CNRS UMR7225
Organization	Inserm
Collaborations	
Funding	
Funding status	Public
Details	Fondation de France
Governance of the database	
Sponsor(s) or organisation(s) responsible	INSERM - Institut National de la Santé et de la Recherche Médicale
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
Database objective	
Main objective	To form a cohort of clinically well evaluated patients with autistic disorders. To identify genetic factors involved in autism spectrum disorders. To establish genotype-phenotype correlations.
Inclusion criteria	Signed consent form. Covered by social security scheme. Autism spectrum disorders
Population type	
Age	Infant (28 days to 2 years) Early childhood (2 to 5 years)

	Childhood (6 to 13 years) Adolescence (13 to 18 years) Adulthood (19 to 24 years) Adulthood (25 to 44 years) Adulthood (45 to 64 years)
Population covered	Sick population
Gender	Male Woman
Geography area	Local
French regions covered by the database	Île-de-France
Detail of the geography area	Pitié-Salpêtrière
Data collection	
Dates	
Date of first collection (YYYY or MM/YYYY)	2009
Size of the database	
Size of the database (number of individuals)	< 500 individuals
Details of the number of individuals	200
Data	
Database activity	Current data collection
Type of data collected	Clinical data Biological data
Clinical data (detail)	Direct physical measures Medical registration
Biological data (detail)	Fragile X karyotype
Presence of a biobank	Yes
Contents of biobank	DNA
Details of biobank content	DNA
Health parameters studied	Health event/morbidity

Procedures

Data collection method	Interview with patient or their parents during genetic counselling Clinical examination
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Participant monitoring	Yes
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Details on monitoring of participants	Genetic counselling
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Links to administrative sources	No
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Promotion and access

Promotion

Link to the document	http://www.ncbi.nlm.nih.gov/pubmed/23092983
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Link to the document	http://www.ncbi.nlm.nih.gov/pubmed/23632794
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Access

Terms of data access (charter for data provision, format of data, availability delay)	C. Nava, B. Keren, C. Mignot A. Rastetter, S. Chantot-Bastaraud, A. Faudet, C. Amiet, C. Laurent, A. Jacqueline, S. Whalen, A. Afenjar, D. Périsset, D. Doummar, N. Dorison, M. Leboyer, J.P. Siffroi, D. Cohen, A. Brice, D. Héron, C. Depienne. Prospective diagnostic analysis using SNP microarrays in patients with autism spectrum disorders. Submitted to EJHG. C. Nava, F. Lamari, D. Héron, C. Mignot, A. Rastetter, B. Keren, D. Cohen, A. Faudet, D. Bouteiller, M. Gilleron, A. Jacqueline, S. Whalen, A. Afenjar, D. Périsset, C. Laurent, C. Dupuits, C. Gautier, M. Gérard, G. Huguet, S. Caillet, B. Leheup, M. Leboyer, C. Gillberg, R. Delorme, T. Bourgeron, A. Brice, C. Depienne. Analysis of the chromosome X exome in patients with Autism Spectrum Disorders identified novel candidate genes including TMLHE. Translational Psychiatry (going to press).
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Access to aggregated data	Access on specific project only
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Access to individual data	Access on specific project only
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