AUTISME - Study of genetic factors implied into autism and related disorders

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General

Identification

Detailed name	Study of genetic factors implied into autism and related disorders
Sign or acronym	AUTISME
CNIL registration number, number and date of CPP agreement, AFSSAPS (French Health Products Safety Agency) authorisation	DR-2013-303

General Aspects

Medical area	Neurology Psychology and psychiatry
Health determinants	Genetic
Others (details)	Autism

Scientific investigator(s) (Contact)

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Collaborations

Participation in projects, networks and consortia	Yes

Funding

Funding status	Mixed
Details	10 % INSERM, AP-HP FONDATION ORANGE, FONDATION FONDAMENTAL

Governance of the database

Sponsor(s) or organisation(s) responsible	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)	Case control study
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. Other organizations actives in the constitution of the cohort: European collaboration Paris, CIC Mondor for adult controls. End of inclusions : 01/01/2019

Database objective	
Main objective	Identify genetic factors implied into autism and related disorders. Secondary objectives: - Carry on the recruitment of patients and related ; - Identify and take an inventory of secondary autism spectrum disorder forms to genetic diseases ; - Study clinical, cognitive and biomedical phenotypes of patients and relatives ; - Carry on the study of genes implied in autism ; - Study genotype/phenotype correlations.
Inclusion criteria	Of patients or subjects called proposers : - patient with autism, filling DSM-IV (American Psychiatric Association, 1994) diagnostic criteria, and ADI-R (Autism Diagnostic interview-revised, Lord et Coll., 1994) for autism Or Patient with Asperger syndrome, filling DM-IV criteria, as well as ASDI (Asperger Syndrome Diagnostic Interview, Gillberg et Coll., 2001) for Asperger syndrome Or Patient with TSA-NS filling DSM-IV diagnostic criteria; - At least 2 years old, with no further age limit ; - Somatic condition compatible with a blood sample; - Social security scheme membership - Informed consent signature. Of first degree relatives (parents, brothers and sisters): - Informed consent signature - Somatic and intellectual condition compatible with a blood sample - Social security scheme membership Of adult controls: - Aged between 18 and 50; - Being Caucasian; - Absence of psychiatric pathology, verified with DIGS (Diagnostic Interview for Genetic Studies, Nurnberger et coll., 1994) for adults; - Somatic and intellectual condition compatible with a blood sample - Informed consent signature - Social security scheme membership Of child controls:

	- At least 2 years old, with no further age limit; - Being Caucasian; - Beneficiary of social security scheme; - Absence of psychiatric pathology verified with Kiddie-sads (kiddie schedule for affective disorders and schizophrenia for school-age children, Orvaschel et Coll., 1982); - Parents or legal guardians informed consent signature
Population type	
Age	Childhood (6 to 13 years) Adolescence (13 to 18 years)
Population covered	Sick population
Gender	Woman
Geography area	National
Detail of the geography area	8 centers in France (+international collaborations)
Data collection	
Dates	
Date of first collection (YYYY or MM/YYYY)	01/1995
Size of the database	
Size of the database (number of individuals)	[1000-10 000[individuals
Details of the number of individuals	1800
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
Details of collected clinical data	Clinical examination at inclusion and every year during the follow-up: - Medical and psychiatric

	history (personal, family) - Biological examinations - Diagnostic evaluation
Declarative data (detail)	Paper self-questionnaire Face to face interview
Details of collected declarative data	Clinical examination at inclusion and every year during the follow-up: - Medical and psychiatric history (personal, family) - Biological examinations - Diagnostic evaluation
Paraclinical data (detail)	Photos of hands, face and feet
Biological data (detail)	Saliva and blood for neurotransmitter level and genetic analysis
Presence of a biobank	Yes
Contents of biobank	Blood cells isolated DNA
Details of biobank content	DNA bank, cell cultures
Health parameters studied	Health event/morbidity Health event/mortality
Procedures	
Data collection method	Self-questionnaire: manually filled paper questionnaire Interviews: manually filled paper questionnaire Clinical examination: handwritten Biological exams: handwritten
Quality procedure(s) used	Coherence request during after computer data entry; Missing data management; Doctors remainders for follow-up visits; Patients receive written information about the use of their data.
Participant monitoring	Yes
Details on monitoring of participants	3 years
Links to administrative sources	No
Promotion and access	
Promotion	
Access	
Terms of data access (charter	Possible data utilization by academic teams. Access

for data provision, format of data, availability delay)	condition : international USA collaboration (Autism Genome Project) leading to publications. Data exploitation not available for industry sectors.
Access to aggregated data	Access on specific project only
Access to individual data	Access on specific project only