

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 reminders 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