CoF-AT - French Cohort Study on Ataxia Telangiectasia

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General

Identification

Detailed name	French Cohort Study on Ataxia Telangiectasia
Sign or acronym	CoF-AT
CNIL registration number, number and date of CPP agreement, AFSSAPS (French Health Products Safety Agency) authorisation	Avis CCPRB n°1989 du 26/07/2002, avis CNIL n°902310 du 30/12/2002, Avis CCTIS n°02.256 du 04/09/2002

General Aspects

Medical area	Cancer research
Health determinants	Genetic
Keywords	Health episodes, cancer, environment

Scientific investigator(s) (Contact)

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Organization	INSERM
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Collaborations

Participation in projects, networks and consortia	Yes

Funding

Funding status	Mixed
Details	Ministère de la Recherche, Inserm, Conseil Scientifique de Radioprotection de EDF, MGEN, Fondation de France, Ligue Nationale contre le Cancer, Aviesan/ITMO, CEST de l'Institut Curie

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)	Cohort 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 bodies active in creating this cohort: Institut Curie, INSERM Inclusion cut-off date: 01/01/2014

Database objective

Main objective	The objectives of the cohort involving women related to a child suffering from ataxia telangiectasia (AT) are multi-layered: 1. To monitor female relatives for early detection of breast cancer (BC). 2. To estimate the risk of cancer associated with AT genes with a focus on BC risk. To investigate the role of potential modifying factors for this risk such as radiation, hormonal factors etc. 3. To investigate the natural history of BC in AT heterozygous women

Inclusion criteria	Breast cancer free women, of legal age and related to a child with ataxia telangiectasia-: mothers, sisters, aunts, grandmothers, maternal and paternal cousins. Recruited from families who participated in the first previous retrospective study by the team and new families contacted through treating physicians (paediatricians, neuro-paediatricians ...), geneticists, the AT research association (APRAT), Orphanet (information server on rare diseases and orphan drugs) and CEREDIH (reference centre for hereditary immunodeficiencies).
Population type	
Age	Adulthood (19 to 24 years) Adulthood (25 to 44 years) Adulthood (45 to 64 years)
Population covered	General population
Gender	Woman
Geography area	International
Detail of the geography area	International multicentric cohort (31 centres): Belgium, Luxembourg, France
Data collection	
Dates	
Date of first collection (YYYY or MM/YYYY)	01/2003
Date of last collection (YYYY or MM/YYYY)	2024
Size of the database	
Size of the database (number of individuals)	< 500 individuals
Details of the number of individuals	391 (2013)
Data	
Database activity	Current data collection
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
Paraclinical data (detail)	Imaging
Biological data (detail)	Type of samples taken: blood, tumour tissues
Presence of a biobank	Yes
Contents of biobank	Plasma Tissues Cell lines DNA DNAc/RNAm
Details of biobank content	Plasma bank, DNA bank, RNA of lymphoblasts, DMSO frozen cells, cell lines, tumour tissue sample (breast cancer)
Health parameters studied	Health event/morbidity Health event/mortality

Procedures

Data collection method	Self-administered questionnaire: from paper questionnaire Interview: from paper questionnaire
Participant monitoring	Yes
Details on monitoring of participants	Follow-up duration: 10 years
Links to administrative sources	No

Promotion and access

Promotion

Link to the document	http://www.hal.inserm.fr/COFAT/
Description	List of publications in HAL

Access

Terms of data access (charter for data provision, format of data, availability delay)	Data may be used by academic teams Data may not be used by industrial teams

Access to aggregated data	Access on specific project only
Access to individual data	Access on specific project only