

# 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
Name of the director	Stoppa-Lyonnet
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### Collaborations

Participation in projects, networks and consortia	Yes
<b>Funding</b>	
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
<b>Governance of the database</b>	
Sponsor(s) or organisation(s) responsible	Institut National de la Santé et de la Recherche Médicale
Organisation status	Public
<b>Additional contact</b>	
<b>Main features</b>	
<b>Type of database</b>	
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
<b>Database objective</b>	
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).
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## Population type

Age	Adulthood (19 to 24 years) Adulthood (25 to 44 years) Adulthood (45 to 64 years)
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Population covered	General population
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Gender	Woman
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Geography area	International
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Detail of the geography area	International multicentric cohort (31 centres): Belgium, Luxembourg, France
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## Data collection

### Dates

Date of first collection (YYYY or MM/YYYY)	01/2003
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Date of last collection (YYYY or MM/YYYY)	2024
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### Size of the database

Size of the database (number of individuals)	< 500 individuals
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Details of the number of individuals	391 (2013)
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### Data

Database activity	Current data collection
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Type of data collected	Clinical data Declarative data
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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