

COPARK - Prospective Follow-Up of Population with Parkinson's Disease - COPARK Cohort

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Last update : 08/13/2014 | Version : 2 | ID : 60119

General

Identification

Detailed name Prospective Follow-Up of Population with Parkinson's Disease - COPARK Cohort

Sign or acronym COPARK

CNIL registration number, number and date of CPP agreement, AFSSAPS (French Health Products Safety Agency) authorisation Accord CNIL

General Aspects

Medical area Neurology

Health determinants Genetic

Keywords Parkinson's symptoms, activities, daily life, Health episodes, quality of life, treatment, mortality

Scientific investigator(s) (Contact)

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Organization CHU DE

Collaborations

Participation in projects, networks and consortia Yes

Funding

Funding status Mixed

Details START UP LN PHARMA , ASSOCIATION DE MALADES, INDUSTRIES, INSERM, CHU DE TOULOUSE

Governance of the database

Sponsor(s) or organisation(s) responsible LN PHARMA

Organisation status Private

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. Inclusion method: Prospective Other bodies active in creating this cohort: CHU, CHG, INDEPENDENT PHYSICIANS Closing date for inclusion: 01/01/2009

Database objective

Main objective General objective: The objective of this multi-disciplinary project (neurology, pharmacology, epidemiology etc.) is to prospectively gather data in a population of outpatients with Parkinson's disease identified through a regional network of hospital neurologists and independent physicians, concerning the onset and progression of motor signs (tremor, akinesia, rigidity, motor complications, freezing, falls, dysarthria ...) and non-motor signs (pain, anxiety and depressive symptoms, autonomic dysfunction, sleep disorders, dementia, apathy, fatigue ...) of PD using validated scales. We will also gather data on quality of life, treatment (care sought and consumption of

medication), morbidity and mortality within the same population. Secondary objective: To develop a biobank in the second phase based on phenotypic and pharmacological characterisations outlined in the COPARK population

Inclusion criteria

Parkinson's patients with idiopathic Parkinson's disease (UKPDBB criteria) Over 18 years of age, non-institutionalised, with no atypical Parkinsonian syndrome, having never undergone neurosurgery, with no cognitive impairment (MMSE <24), with no serious life-threatening pathology, who have given signed informed consent.

Population type

Age

Elderly (65 to 79 years)
Great age (80 years and more)

Population covered

Sick population

Gender

Male
Woman

Geography area

Regional

French regions covered by the database

Aquitaine Limousin Poitou-Charentes
Languedoc-Roussillon Midi-Pyrénées
Nord - Pas-de-Calais Picardie
Pays de la Loire

Detail of the geography area

4 REGIONS THROUGHOUT FRANCE (MIDI-PYRENEES, AQUITAINE, PAYS DE LOIRE, NORD PAS DE CALAIS)

Data collection

Dates

Date of first collection (YYYY or MM/YYYY)

12/2006

Date of last collection (YYYY or MM/YYYY)

01/2013

Size of the database

Size of the database (number of individuals)

< 500 individuals

Details of the number of individuals

467

Data

Database activity Current data collection

Type of data collected Clinical data
Declarative data

Clinical data (detail) Direct physical measures
Medical registration

Declarative data (detail) Paper self-questionnaire

Presence of a biobank No

Health parameters studied Health event/morbidity
Health event/mortality

Procedures

Data collection method Self-administered questionnaire: Entry from a paper questionnaire (Manual input) with double data entry
Interview: Entry from paper questionnaire (manual input) with double data entry
Clinical Examinations: Handwritten (Manual input) and double data entry

Participant monitoring Yes

Details on monitoring of participants Follow-up duration: 5 years

Links to administrative sources No

Promotion and access

Promotion

Link to the document [http://www.ncbi.nlm.nih.gov/pubmed/?term=%28copark+AND+Rascol+O\[Author\]%29+OR+24839938\[uid\]](http://www.ncbi.nlm.nih.gov/pubmed/?term=%28copark+AND+Rascol+O[Author]%29+OR+24839938[uid])

Description List of publications in Pubmed

Access

Terms of data access (charter for data provision, format of data, availability delay)

Data may be used by academic teams Data access for research members and non-members under contract approved by the cohort Scientific Committee and according to the terms governing the charter between different partners Data may be used by industrial teams Data access for research members and non-members under contract that are approved by the cohort Scientific Committee

and according to the terms governing the charter between different partners

Access to aggregated data

Access on specific project only

Access to individual data

Access on specific project only