

GENESIS - Genetics nephropathy and sib pair study

Head :Marre Michel, U695

Hadjaj , U695

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General

Identification

Detailed name Genetics nephropathy and sib pair study

Sign or acronym GENESIS

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

CNIL

General Aspects

Medical area Endocrinology and metabolism
Urology, andrology and nephrology

Health determinants Genetic

Keywords Renal insufficiency, myocardial infarction, diabetes

Scientific investigator(s) (Contact)

Name of the director Marre

Surname Michel

Email michel.marre@bch.aphp.fr

Unit U695

Organization Institut National de la Santé et de la Recherche

Name of the director Hadjaj

Email s.hadjadj@chu-poitiers.fr

Unit U695

Organization Institut National de la Santé et de la Recherche

Collaborations

Participation in projects, networks and consortia	Yes
Funding	
Funding status	Mixed
Details	Programme hospitalier de recherche clinique Institut national de la santé et de la recherche médicale Association ADRV Paris France Association GEMMS, Poitiers, France
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.	Inclusion mode: prospective. Other organizations actives in the constitution of the cohort: the clinical research technician: Mme C. DEMER, CHU of Poitiers - places: endocrinology services - CHU of Poitiers (maintenance of the database) - INSERM U695: bio-bank localization. End of inclusions : 01/01/2001
Database objective	
Main objective	GENESIS study, aiming to complete the GENEDIAB study (genetics, nephropathy, diabetes) and the angevan mono-centric cohort Surgene, recruited in a transversal way type 1 diabetic patients presenting a diabetic nephropathy or protected against diabetic nephropathy and proposed them to

include their related.

The objective of the cohort has been to follow longitudinally the cardiovascular and renal future of type 1 diabetic patients, 4 to 8 years after their inclusion

Inclusion criteria	Type 1 diabetes+retinopathy at all stages+diabetic nephropathy or normo-albuminuria and normal kidney function.
Population type	
Age	Adulthood (19 to 24 years) Adulthood (25 to 44 years) Adulthood (45 to 64 years)
Population covered	Sick population
Gender	Male Woman
Geography area	International
Detail of the geography area	International multi-centric cohort (13 centers), including Belgium and France
Data collection	
Dates	
Date of first collection (YYYY or MM/YYYY)	01/1998
Date of last collection (YYYY or MM/YYYY)	01/2006
Size of the database	
Size of the database (number of individuals)	[1000-10 000[individuals
Details of the number of individuals	1064
Data	
Database activity	Current data collection
Type of data collected	Clinical data Biological data
Clinical data (detail)	Direct physical measures

Medical registration

Details of collected clinical data Clinical examination at inclusion and during the follow-up. Information collected during the examination: weight, size, blood pressure, cardiovascular and renal events. If death, date and cause (medical specialist or general practitioner)

Biological data (detail) Samples: serum creatinine, urinary albumin excretion, HBA1C

Presence of a biobank Yes

Contents of biobank Serum
Plasma
Fluids (saliva, urine, amniotic fluid, ?)
DNA

Details of biobank content Serum, plasma, DNA, urine bank

Health parameters studied Health event/morbidity
Health event/mortality

Procedures

Data collection method Clinical examinations: hand-written step (manual entry)

Quality procedure(s) used Coherence request during after computer data entry. Follow-up data are considered with the last date as a closure date.

Participant monitoring Yes

Details on monitoring of participants 6 years follow-up

Links to administrative sources No

Promotion and access

Promotion

Link to the document <http://tinyurl.com/Pubmed-GENESIS>

Description List of publications in Pubmed

Access

Terms of data access (charter for data provision, format of data, availability delay) To be defined iwth the scientific investigator

Access to aggregated data

Access on specific project only

Access to individual data

Access on specific project only