GENESIS - Genetics nephropathy and sib pair study

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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)

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Unit	U695
Organization	Institut National de la Santé et de la Recherche
Name of the director	Hadjaj
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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 cliniqueInstitut national de la santé et de la recherche médicaleAssociation ADRV Paris FranceAssociation 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