

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

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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)
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Biological data (detail)	Samples: serum creatinine, urinary albumin excretion, HBA1C
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Presence of a biobank	Yes
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Contents of biobank	Serum Plasma Fluids (saliva, urine, amniotic fluid, ?) DNA
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Details of biobank content	Serum, plasma, DNA, urine bank
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Health parameters studied	Health event/morbidity Health event/mortality
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Procedures

Data collection method	Clinical examinations: hand-written step (manual entry)
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Quality procedure(s) used	Coherence request during after computer data entry. Follow-up data are considered with the last date as a closure date.
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Participant monitoring	Yes
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Details on monitoring of participants	6 years follow-up
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Links to administrative sources	No
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Promotion and access

Promotion

Link to the document	http://tinyurl.com/Pubmed-GENESIS
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Description	List of publications in Pubmed
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Access

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

Access on specific project only

Access to individual data

Access on specific project only