

CEREDIH - French National Registry for Primary Immunodeficiencies

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(Développement normal et pathologique du système immunitaire) Fondation Imagine

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General	
Identification	
Detailed name	French National Registry for Primary Immunodeficiencies
Sign or acronym	CEREDIH
CNIL registration number, number and date of CPP agreement, AFSSAPS (French Health Products Safety Agency) authorisation	CNIL n°1165361 (28/04/2006)
General Aspects	
Medical area	Immunology Rare diseases
Health determinants	Genetic
Others (details)	all pathologies characterized by qualitative and/or quantitative abnormalities of the immune system, bringing about a increased susceptibility to infections, autoimmunity and cancer
Keywords	primary immunodeficiency, rare disease, immune system, autoimmunity, genetic anomaly, infection, cancer
Scientific investigator(s) (Contact)	
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Unit	CEREDIH Centre de référence Déficits Immunitaires Héréditaires INSERM U768 (Développement normal et pathologique du système immunitaire) Fondation Imagine
Organization	APHP
Collaborations	
Funding	
Funding status	Mixed
Details	Ministry of Health, Co-Funding by pharmaceutical firms and Patients' association donations
Governance of the database	
Sponsor(s) or organisation(s) responsible	APHP
Organisation status	Public
Additional contact	
Main features	
Type of database	
Type of database	Morbidity registers
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
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Database objective

Main objective	The main objective of the French national registry for primary immunodeficiency (PID) is to list all patients - living or deceased - who are suffering or have suffered from these diseases in France so as to estimate and monitor their prevalence, incidence, demographic characteristics, age at diagnosis, period of time between first symptoms and diagnosis, survival and mortality.
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Inclusion criteria	Alive and deceased patients with primary immunodeficiency in France
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Population type

Age	Newborns (birth to 28 days) Infant (28 days to 2 years) Early childhood (2 to 5 years) Childhood (6 to 13 years) Adolescence (13 to 18 years) Adulthood (19 to 24 years) Adulthood (25 to 44 years) Adulthood (45 to 64 years) Elderly (65 to 79 years) Great age (80 years and more)
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Population covered	Sick population
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Gender	Male Woman
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Geography area	National
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Detail of the geography area	Metropolitan France and overseas departments/territories
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Data collection

Dates

Date of first collection (YYYY or MM/YYYY)	01/2006
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Size of the database

Size of the database (number of individuals)	[1000-10 000] individuals
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Details of the number of individuals	664 en 2006, 1370 en 2007, 815 en 2008 et 411 en 2009, ce qui faisait un total de 3360 cas au 1er janvier 2010 Nombre de nouveaux cas attendus par an dans cette population estimé à : 160 (fréquence : 1/5000 et 800 000 naissances/an) 664 in 2006, 1,370 in 2007, 815 in 2008 and 411 in 2009, making a total of 3,360 cases as at January 1st 2010. Number of new cases expected per year in this population estimated to be: 160 (frequency: 1/5,000 and 800,000 births/year)
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Data

Database activity	Current data collection
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Type of data collected	Clinical data Paraclinical data Biological data Administrative data
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Clinical data (detail)	Direct physical measures
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Paraclinical data (detail)	Imaging, Pathology
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Biological data (detail)	CBC, Ig quantitation assay, Lymphocyte phenotyping, Genetic analyses
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Administrative data (detail)	Follow-up hospital, Contact physician, Competence center, Patient consent, Place of residence
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Presence of a biobank	No
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Health parameters studied	Health event/morbidity Health event/mortality Quality of life/health perception
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Procedures

Participant monitoring	Yes
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Details on monitoring of participants	Case follow-up is carried out once a year.
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Links to administrative sources	No
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Promotion and access

Promotion

Link to the document	http://www.ceredih.fr
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Access

Terms of data access (charter for data provision, format of data, availability delay)	Annual national meeting, website, mail contact for CEREDIH manager If a team wished to work on the registry's data, the project would have to be submitted to the CEREDIH scientific advisory board.
Access to aggregated data	Access on specific project only
Access to individual data	Access on specific project only