

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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Organization	APHP

Collaborations

Funding

Funding status	Mixed
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Details	Ministry of Health, Co-Funding by pharmaceutical firms and Patients' association donations
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Governance of the database

Sponsor(s) or organisation(s) responsible	APHP
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Organisation status	Public
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Additional contact

Main features

Type of database

Type of database	Morbidity registers
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Database recruitment is carried out by an intermediary	A selection of health institutions and services
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Database recruitment is carried out as part of an interventional study No

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.

Inclusion criteria Alive and deceased patients with primary immunodeficiency in France

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)

Population covered Sick population

Gender Male
Woman

Geography area National

Detail of the geography area Metropolitan France and overseas departments/territories

Data collection

Dates

Date of first 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	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