- Hereditary Ichthyosis Cohort

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General

Identification

Detailed name	Hereditary Ichthyosis Cohort
CNIL registration number, number and date of CPP agreement, AFSSAPS (French Health Products Safety Agency) authorisation	en cours

General Aspects

Health determinants	Genetic
Others (details)	Ichthyosis
Keywords	Hereditary, progression, complications

Scientific investigator(s) (Contact)

Name of the director	Mazereeuw-Hautier
Surname	Juliette
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Organization	CHU
Name of the director	Jonca
Surname	Nathalie

Collaborations

Funding

Funding status	Mixed
Details	Financement ministériel du centre de référence maladies rares pour du personnel.

Governance of the database

Sponsor(s) or organisation(s) responsible	CHU Toulouse
Organisation status	Public

Additional contact

Main features

Type of database

Type of database	Study databases
Study databases (details)	Longitudinal study (except cohorts)
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.	All patients with this disease are included

Database objective

Main objective	To form a usable database for hereditary ichthyosis on which to base future research projects, such as epidemiological, clinical (disease progression follow-up and onset of complications) physiopathological or therapeutic projects.
Inclusion criteria	All hereditary ichthyosis patients, regardless of clinical type, severity, age, gender, disease

	progression or treatment (to ensure a broad representative cohort). Patients attending consultation or hospitalised during their first visit or medical follow-up in the Referral Centre or other centres throughout France. Signed consent to participate in the study.
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	France
Data collection	
Dates	
Date of first collection (YYYY or MM/YYYY)	09/2009
Size of the database	
Size of the database (number of individuals)	< 500 individuals
Details of the number of individuals	100
Data	
Database activity	Current data collection
Type of data collected	Clinical data Declarative data Paraclinical data Biological data Administrative data

Clinical data (detail)	Direct physical measures Medical registration
Declarative data (detail)	Face to face interview
Paraclinical data (detail)	Data collected from regular patient follow-up
Biological data (detail)	Regular biological monitoring
Administrative data (detail)	Socio-demographic data
Presence of a biobank	Yes
Contents of biobank	Whole blood Tissues DNA
Details of biobank content	Blood and skin samples
Health parameters studied	Health event/morbidity Health event/mortality Health care consumption and services Quality of life/health perception
Care consumption (detail)	Hospitalization Medical/paramedical consultation Medicines consumption

Procedures

Data collection method	By physician during annual visit. Data are recorded in real-time in an Excel database for clinical and biological characteristics.
Participant monitoring	Yes
Details on monitoring of participants	Re-assessment of patient's clinical and biological characteristics and quality of life during regular follow-up visit (normally an annual visit). Follow-up over 10 years.
Links to administrative sources	No

Promotion and access

Promotion

Access

Terms of data access (charter for data provision, format of	Publications: Data available between CRMRP and INSERM teams. The creation of a database allows

data, availability delay)	ichthyosis studies to be carried out jointly by these units. The transfer of data to other parties for research purposes is not planned unless part of a collaborative project.
Access to aggregated data	Access on specific project only
Access to individual data	Access on specific project only