- French Registry on Biliary Atresia

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General

Identification

Detailed name	French Registry on Biliary Atresia
CNIL registration number, number and date of CPP agreement, AFSSAPS (French Health Products Safety Agency) authorisation	CNIL (approval no. 997085)

General Aspects

Medical area	Endocrinology and metabolism Pediatrics Radiology and medical imaging Rare diseases
Pathology (details)	Biliary atresia
Keywords	biliary atresia, therapy, registry, children, epidemiology

Scientific investigator(s) (Contact)

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Organization	Necker Hospital for Sick Children

Collaborations

Participation in projects, networks and consortia	Yes

Details	European Federation for Biliary Atresia Research
Funding	
Funding status	Public
Details	PHRC AOM 02007
Governance of the database	
Sponsor(s) or organisation(s) responsible	Observatoire français de l'atrésie des voies biliaires
Organisation status	Private
Additional contact	
Main features	
Type of database	
Type of database	Morbidity registers
Additional information regarding sample selection.	Involvement of 45 centres participating in BA treatment (from diagnosis to liver transplantation).
Database objective	
Main objective	The aim of this registry is to promote research, therapeutic progress, information on family and medical training in the area of biliary atresia and related pathologies.
Inclusion criteria	Confirmed BA diagnosis confirmed. Children living in France born between 1986 and 2009.
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)
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)	1986

Size of the database

Size of the database (number of individuals)	[1000-10 000[individuals
Details of the number of individuals	1,107 (2009)

Data

Database activity	Current data collection
Type of data collected	Clinical data Biological data
Clinical data (detail)	Direct physical measures
Details of collected clinical data	Identity of children (first name, last name, date of birth, address), team or teams providing medical care; diagnostic circumstances; Kasai procedure and outcomes; possible liver transplantation and outcomes; outcome for the child.
Biological data (detail)	Biliary remnants
Presence of a biobank	No
Health parameters studied	Health event/morbidity

Procedures

Participant monitoring	No
Links to administrative sources	No

Promotion and access

Promotion

Link to the document	http://asso.orpha.net/OFAVB/__PP__5.html

Access

Terms of data access (charter for data provision, format of	Contact the scientist in charge.

data, availability delay)	
Access to aggregated data	Access on specific project only
Access to individual data	Access on specific project only