

APICALE-AJI - Auvergne-Loire observatory on chronic inflammatory diseases of the musculoskeletal system occurring in childhood - Arthrites Juvéniles Idiopathiques cohort (long-term follow-up of children with juvenile idiopathic arthritis)

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General	
Identification	
Detailed name	Auvergne-Loire observatory on chronic inflammatory diseases of the musculoskeletal system occurring in childhood - Arthrites Juvéniles Idiopathiques cohort (long-term follow-up of children with juvenile idiopathic arthritis)
Sign or acronym	APICALE-AJI
CNIL registration number, number and date of CPP agreement, AFSSAPS (French Health Products Safety Agency) authorisation	CNIL en cours
General Aspects	
Medical area	Rheumatology
Health determinants	Climate
Others (details)	Juvenile Idiopathic Arthritis
Keywords	Very long-term progression of children with Juvenile Idiopathic Arthritis (AJI), transition period, joint disease, repercussions
Scientific investigator(s) (Contact)	
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Organization	CHU Clermont-Ferrand / INSERM - Institut National de Santé et Recherche
Collaborations	
Funding	
Funding status	Public
Details	Le programme hospitalier de recherche clinique local 2009
Governance of the database	
Sponsor(s) or organisation(s) responsible	CHU Clermont-Ferrand
Organisation status	Public
Sponsor(s) or organisation(s) responsible	INSERM
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
Database objective	
Main objective	The primary objective of this project is to describe the very long-term progression of Juvenile Idiopathic Arthritis (AJI) in children, from onset of the disease until adulthood that extends past the transition period. The follow-up will particular focus on joint disease activity as well as very long-term repercussions.- The secondary objectives will be to provide data relating to treatment effectiveness and tolerance, especially concerning the outcome for children intolerant to methotrexate and the monitoring children in biotherapy. - This follow-up will also aid articulation between research and practice by proposing further studies in 3 areas: o nursing research and therapeutic education o study of bone microarchitecture o study of endothelial function and vascular abnormalities
Inclusion criteria	Children with Juvenile Idiopathic Arthritis (AJI) from the Auvergne-Loire region
Population type	
Age	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	Regional
French regions covered by the database	Auvergne Rhône-Alpes
Detail of the geography area	Auvergne-Loire
Data collection	
Dates	

Date of first collection (YYYY or MM/YYYY) 2011

Size of the database

Size of the database (number of individuals) < 500 individuals

Details of the number of individuals 165 (08/2014)

Data

Database activity Current data collection

Type of data collected Clinical data
Declarative data

Clinical data (detail) Direct physical measures

Declarative data (detail) Paper self-questionnaire

Presence of a biobank No

Health parameters studied Health event/morbidity
Health event/mortality
Health care consumption and services

Care consumption (detail) Hospitalization
Medical/paramedical consultation
Medicines consumption

Procedures

Data collection method Follow-up log. Patient data will be sent by post to the coordinating centre (CHU de Clermont-Ferrand). Data input will be carried out annually Access designed for this purpose

Participant monitoring Yes

Details on monitoring of participants Follow-up will be for as long as possible with no definite duration. Follow-up initiated during childhood will continue to adulthood.

Links to administrative sources No

Promotion and access

Promotion

Link to the document <http://www.ncbi.nlm.nih.gov/pubmed/21544583>

Access

Terms of data access (charter for data provision, format of data, availability delay)

Considered publications: - 2012-2013: prévalence de la maladie et trajectoire initiale des patients - 2013: facteurs de risque de l'intolérance au methotrexate et devenir des enfants intolérants au methotrexate - 2014/2015: modifications thérapeutiques immédiatement au-décours de la transition

Access to aggregated data

Access on specific project only

Access to individual data

Access on specific project only