

# 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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## Collaborations

## Funding

Funding status	Public
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Details	Le programme hospitalier de recherche clinique local 2009
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## Governance of the database

Sponsor(s) or organisation(s) responsible	CHU Clermont-Ferrand
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Organisation status	Public
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Sponsor(s) or organisation(s) responsible	INSERM
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Organisation status	Public
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## Additional contact

## Main features

## Type of database

Type of database	Study databases
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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
<b>Database objective</b>	
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
<b>Population type</b>	
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
<b>Data collection</b>	
<b>Dates</b>	

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