

# FRALim - Registry on Amyotrophic Lateral Sclerosis (ALS) in Limousin

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## General

### Identification

Detailed name Registry on Amyotrophic Lateral Sclerosis (ALS) in Limousin

Sign or acronym FRALim

CNIL registration number, number and date of CPP agreement, AFSSAPS (French Health Products Safety Agency) authorisation CNIL: 911038 (June 2011); CCTIRS: 10487 bis (January 2011)

### General Aspects

Medical area Disability/handicap  
Neurology  
Rare diseases

Pathology (details) Amyotrophic lateral sclerosis

Health determinants Genetic

Keywords amyotrophic lateral sclerosis; ALS; Limousin; treatment; registry

### Scientific investigator(s) (Contact)

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## Collaborations

Participation in projects, networks and consortia	Yes
Details	EURALS (European ALS Consortium)

## Funding

Funding status	Public
Details	National Research Agency; ALS Research Association; Limousin - Poitou - Charentes Centre for Research and Higher Education

## Governance of the database

Sponsor(s) or organisation(s) responsible	UMR Inserm 1094 NET, Limoges
Organisation status	Public
Presence of scientific or steering committees	Yes
Labelling and database evaluation	Steering Committee at Inserm UMR 1094

## Additional contact

## Main features

### Type of database

Type of database Morbidity registers

### Database objective

Main objective To improve the epidemiological and clinical description of ALS in France.

Inclusion criteria Patients with ALS identified by one of the following 3 sources: The French national body coordinating ALS referral centres; public and private hospitals in the Limousin region; health insurance data.

### Population type

Age 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 Regional

French regions covered by the database Aquitaine Limousin Poitou-Charentes

Detail of the geography area Limousin

## Data collection

### Dates

Date of first collection (YYYY or MM/YYYY) 2000

### Size of the database

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

Details of the number of individuals 322

### Data

Database activity	Current data collection
Type of data collected	Clinical data Administrative data
Details of collected clinical data	Start site; familial ALS vs. sporadic ALS
Administrative data (detail)	Personal demographic data (name, age, sex, address), medical data (treatment start date, treating physician, Airlie House diagnostic classification).
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
<b>Procedures</b>	
Data collection method	Retrospective from medical administrative data.
Quality procedure(s) used	The collaborating centre for methodology is CEBIMER (Centre of epidemiology, biostatistics and research methodology), Limoges University Hospital, led by Prof. Preux; Dr. Marin, deputy head of the Capture-R System Management software.
Participant monitoring	Yes
Links to administrative sources	Yes
<b>Promotion and access</b>	
<b>Promotion</b>	
Link to the document	<a href="http://onlinelibrary.wiley.com/doi/10.1111/ene.12474/abstract;jsessionid=4DA9D9A2A656588F1CED30D101B2B8D9.f02t02">http://onlinelibrary.wiley.com/doi/10.1111/ene.12474/abstract;jsessionid=4DA9D9A2A656588F1CED30D101B2B8D9.f02t02</a>
Link to the document	<a href="http://tinyurl.com/PUBMED-FRAlim">http://tinyurl.com/PUBMED-FRAlim</a>
Link to the document	<a href="http://tinyurl.com/HAL-FRAlim">http://tinyurl.com/HAL-FRAlim</a>
<b>Access</b>	
Terms of data access (charter for data provision, format of data, availability delay)	Available under certain conditions (contact 1 of 3 scientists in charge).

Access to aggregated data

Access on specific project only

Access to individual data

Access on specific project only