# NEAER - National Esophageal Atresia Epidemiologic Registry

Head :Sfeir Rony, Reference center for congenital esophageal abnormalities

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## General

### Identification

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|---|---|
| Detailed name | National Esophageal Atresia Epidemiologic Registry |
| Sign or acronym | NEAER |
| CNIL registration number, number and date of CPP agreement, AFSSAPS (French Health Products Safety Agency) authorisation | 908362 |

### General Aspects

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|---|---|
| Medical area | Gastroenterology et hepatology<br>Pediatrics<br>Pneumology<br>Rare diseases |
| Health determinants | Genetic<br>Geography<br>Lifestyle and behavior<br>Nutrition |
| Keywords | esophageal atresia, epidemiology, congenital malformations |

### Scientific investigator(s) (Contact)

| | |
|---|---|
| Name of the director | Sfeir |
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| Unit | Reference center for congenital esophageal abnormalities |
| Organization | CHRU |

### Collaborations

| | |
|---|---|
| Participation in projects, networks and consortia | Yes |

### Funding

| | |
|---|---|
| Funding status | Public |
| Details | Centre de Référence des Affections Congénitales et Malformatives de l'Oesophage |

### Governance of the database

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|---|---|
| Sponsor(s) or organisation(s) responsible | CHR Lille |
| Organisation status | Public |
| Presence of scientific or steering committees | Yes |

### Additional contact

## Main features

### Type of database

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|---|---|
| Type of database | Morbidity registers |
| Additional information regarding sample selection. | Selection of subjects having the required inclusion criteria |

### Database objective

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|---|---|
| Main objective | Objectives of the registry in the area of public health (access to pre and postnatal diagnostics, monitoring, caring for patients, evaluation):<br>1) Determine the prevalence of esophageal atresia and of its various anatomical forms.<br>2) Study the geographical distribution of this malformation<br>3) Determine mortality at one year for this malformation<br>4) Evaluate the disparities in care and the changes between the different centers.<br><br>Objectives of the registry in the areas of therapy and research:<br>1) Evaluate if the percentage of antenatal diagnostic and the earliness in care vary in our country over the next few years. |

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|---|---|
| | 2) Evaluate the effect of the prenatal diagnosis on prevalence.<br>3) Evaluate the modifications that appeared in the care for newborns having esophageal atresia and the influence of the latter on the future of the patients. Recent modifications in care: installation of a transanatomic sensor, early feeding, abandoning parenteral nutrition, could influence the change (duration of hospitalization, complications) and the future at 1 year.<br>4) Evaluate the short-term prognosis (surgical complications, duration of hospitalization, duration of reanimation, etc.).<br>5) Structure and harmonize the care for esophageal atresia across the national territory. |
| Inclusion criteria | Any living newborn with esophageal atresia |

### Population type

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|---|---|
| Age | Newborns (birth to 28 days)<br>Infant (28 days to 2 years) |
| Population covered | Sick population |
| Pathology | Q39 - Congenital malformations of oesophagus |
| Gender | Male<br>Woman |
| Geography area | National |
| Detail of the geography area | Metropolitan France + Overseas Départements/Territories |

## Data collection

### Dates

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|---|---|
| Date of first collection (YYYY or MM/YYYY) | 2008 |

### Size of the database

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|---|---|
| Size of the database (number of individuals) | [1000-10 000[ individuals |
| Details of the number of individuals | 2008 : 149 new cases : enclosed inclusion 2009 : 159 new cases : enclosed inclusion2010 : 96 cases : inclusion in progress |

### Data

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|---|---|
| Database activity | Data collection completed |
| Type of data collected | Clinical data<br>Declarative data<br>Paraclinical data<br>Administrative data |
| Clinical data (detail) | Direct physical measures<br>Medical registration |
| Declarative data (detail) | Paper self-questionnaire<br>Internet self-questionnaire |
| Administrative data (detail) | - 2 first letters Last name and First name - Date of birth- Hospital of origin- Maternity ward of origin-Postal code (Place of residence)- Date of diagnostic-Sex - Département of birth - Age of the mother at birth |
| Presence of a biobank | No |
| Health parameters studied | Health event/morbidity<br>Health event/mortality |

## Procedures

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| Data collection method | Regular requests via telephone, contact through email and mail and trips on-site in the 38 centers that form the Epidemiological Network and research on esophageal atresia. |
| Participant monitoring | Yes |
| Monitoring procedures | Monitoring by contact with the referring doctor |
| Details on monitoring of participants | Vital statusClinical follow-up: clinical data, para-clinical data, morbidity. |
| Links to administrative sources | Yes |
| Linked administrative sources (detail) | department of medical informatic |

## Promotion and access

## Promotion

| | |
|---|---|
| Link to the document | Sfeir et al. - 2013 - Esophageal atresia data from a national cohort.pdf |
| Description | Liste des publications dans Pubmed |

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|---|---|
| Link to the document | EJPS_153585rev (2).pdf |
| **Access** | |
| Terms of data access (charter for data provision, format of data, availability delay) | Scientific publications<br>Congresses and reference center meetings<br>Communication with parents' associations |
| Access to aggregated data | Access on specific project only |
| Access to individual data | Access on specific project only |