NEAER - National Esophageal Atresia Epidemiologic Registry

Head :Sfeir Rony, Reference center for congenital esophageal abnormalities

Organization

Last update : 09/21/2020 Version : 2 ID : 180		
General		
Identification		
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		
Medical area	Gastroenterology et hepatology Pediatrics Pneumology Rare diseases	
Health determinants	Genetic Geography Lifestyle and behavior Nutrition	
Keywords	esophageal atresia, epidemiology, congenital malformations	
Scientific investigator(s) (Contact)		
Name of the director	Sfeir	
Surname	Rony	
Address	1 Place Verdun 59037 Lille cedex	
Phone	+ 33 (0)3 20 44 49 74	
Email	rony.sfeir@chru-lille.fr	
Unit	Reference center for congenital esophageal abnormalities	

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	
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	
Type of database	Morbidity registers
Additional information regarding sample selection.	Selection of subjects having the required inclusion criteria
Database objective	
Main objective	Objectives of the registry in the area of public health (access to pre and postnatal diagnostics, monitoring, caring for patients, evaluation): 1) Determine the prevalence of esophageal atresia and of its various anatomical forms. 2) Study the geographical distribution of this malformation 3) Determine mortality at one year for this malformation 4) Evaluate the disparities in care and the changes between the different centers.
	Objectives of the registry in the areas of therapy and research: 1) Evaluate if the percentage of antenatal diagnostic and the earliness in care vary in our country over the next few years.

- 2) Evaluate the effect of the prenatal diagnosis on prevalence.
- 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.
- 4) Evaluate the short-term prognosis (surgical complications, duration of hospitalization, duration of reanimation, etc.).
- 5) Structure and harmonize the care for esophageal atresia across the national territory.

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Inc	lusion	crite	rıa

Any living newborn with esophageal atresia

Pol	pulatio	n type
10	palacio	TILYPO

Age Newborns (birth to 28 days)
Infant (28 days to 2 years)

Population covered Sick population

Pathology Q39 - Congenital malformations of oesophagus

Gender Male Woman

Geography area National

Detail of the geography area Metropolitan France + Overseas Départements/Territories

Data collection

Dates

Date of first collection (YYYY or MM/YYYY)

2008

Size of the database

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 inclusion 2010: 96 cases

: inclusion in progress

Data

Database activity	Data collection completed
Type of data collected	Clinical data Declarative data Paraclinical data Administrative data
Clinical data (detail)	Direct physical measures Medical registration
Declarative data (detail)	Paper self-questionnaire 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 Health event/mortality
Procedures	
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	email and mail and trips on-site in the 38 centers that form the Epidemiological Network and research
Participant monitoring Monitoring procedures	email and mail and trips on-site in the 38 centers that form the Epidemiological Network and research on esophageal atresia.
	email and mail and trips on-site in the 38 centers that form the Epidemiological Network and research on esophageal atresia. Yes
Monitoring procedures Details on monitoring of	email and mail and trips on-site in the 38 centers that form the Epidemiological Network and research on esophageal atresia. Yes Monitoring by contact with the referring doctor Vital statusClinical follow-up: clinical data, para-
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Monitoring procedures Details on monitoring of participants Links to administrative sources Linked administrative sources	email and mail and trips on-site in the 38 centers that form the Epidemiological Network and research on esophageal atresia. Yes Monitoring by contact with the referring doctor Vital statusClinical follow-up: clinical data, paraclinical data, morbidity. Yes
Monitoring procedures Details on monitoring of participants Links to administrative sources Linked administrative sources (detail)	email and mail and trips on-site in the 38 centers that form the Epidemiological Network and research on esophageal atresia. Yes Monitoring by contact with the referring doctor Vital statusClinical follow-up: clinical data, paraclinical data, morbidity. Yes
Monitoring procedures Details on monitoring of participants Links to administrative sources Linked administrative sources (detail) Promotion and access	email and mail and trips on-site in the 38 centers that form the Epidemiological Network and research on esophageal atresia. Yes Monitoring by contact with the referring doctor Vital statusClinical follow-up: clinical data, paraclinical data, morbidity. Yes

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