International collaboration

..... with organisations working towards better treatments for EA

Establishing a set of new consensus statements for best practice in respiratory care of those born with EA.

A registry specific to EA for measurement of agreed quality indicators shall be progressively implemented across key European hospitals.

Reviews existing practice for initial surgery and up.

Building on recent study findings, identifying good practice, identifying interested adult clinicians, developing awareness training. Also establishing minimum care standards and good practice guidelines for transition and adult care.

An umbrella programme for much ERNICA work, ensuring that all projects address one or more stages of the Patient Journey.

Information on nutrition and feeding, dilatation and reflux.

Regular webinars relevant to both children and adults born with EA on Patient-Reported Outcomes on Quality of Life, latest study findings; impact on families.

> Work to re-cast the consensus statements in language and terms readily understood by patients and their families.

Many of those born with EA also develop serious respiratory problems. **ERN-LUNG** is focussed on rare respiratory diseases and collaborates

on EA

respiratory

guidelines.

statements of best immediate follow-

ERNICA

The Patient Journey Nutrition

Quality of life & Mental health Transition and Adult Care

Consensus statements – Perioperative and follow-up care Consensus statements: Patient – friendly information

> Quality Indicators and Registry Consensus statements - Respiratory

Some of those born with EA were also born with rare urorectal-genital malformations which are the focus of eUROGEN.

ERN - LUNG

Respiratory health

eUROGEN

Covers ARM & Urogenital conditions

ESPGHAN

Esophageal diseases group



Gothenburg Hosa

Patient – Reported Outcomes - QOL

EUPSA

Transition of Care study

INOEA

Advocacy

EURORDIS Rare Diseases International

International EA Conferences Medical advisory support - EAT Transition & Adult care

A survey of hospitals across Europe into how they manage transition and the extent of their adult care for those born with a range of congenital anomalies including EA.

> **ERNICA ESPGHAN**

World's only EA-specific multidisciplinary medical conferences. Delegates from EAT and some national support groups attend.

Identifying existing best practice in paediatric-to-adult transition for EA patients, and developing guidelines. Responds to EA-related medical questions and issues raised via EAT.

Influencing EU and wider official policy on Rare Diseases. EAT special patient rep Graham Slater is a director of EURORDIS.

Outcomes Measures Quality of Life studies, now involving 20 centres globally, led by Gothenburg Children's Hospital. Also forthcoming further study in conjunction with EAT, INoEA, and others.

Patient-Reported

EAT engages with the **Special Interest Group** relevant to EA.

EUPSA

European Network on Inherited and Congenital Anomalies European Society for Paediatric Gastroenterology Hepatology and Nutrition European Paediatric Surgeons' Association

ERN - LUNG **eUROGEN EURORDIS** INoEA

European Network - rare respiratory diseases European Network - rare urogenital diseases & complex conditions **European Rare Diseases Organisation** International Network on Esophagheal Atresia

Pursuing improved treatments for those people born with Esophageal Atresia, EAT collaborates internationally with healthcare and other professionals on behalf of its many nationally-focussed support group members. EAT is a properly-constituted German-registered organisation. It has no staff and all its officers and volunteers are also members of one of the EAT member support groups. Individuals cannot be members of EAT and all support to

individuals is from a national support group. EAT is one of the most active

reference networks on rare diseases (ERNICA. ERN-lung, eUROGEN).

patient – advocacy organisations which is represented at the EU-funded medical



EAT is the (international) Federation of Esophageal Atresia and Tracheo-Esophageal Atresia Support groups.

Long-established national support groups AFAO (France), KEKS (Germany), TOFS (UK) and VOKS (Netherlands) initiated close co-operation in 2010 and EAT was founded by them soon afterwards.

EAT has 14 member support groups in Europe, Africa, South America and Australia. The various support groups also have their own engagements / collaborations in pursuit of improved treatments within their own countries.

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