SACROCOCCYGEAL TERATOMA STUDY PROTOCOL

Introduction

Sacrococcygeal teratoma (SCT) is a rare congenital disorder with an estimated incidence of 1:15,000 to 1:30,000. The treatment is complete resection, but in a substantial proportion of patients the tumor recurs, often as malignancy. There is scanty data on the true recurrence rate of SCT, the timing of recurrence, how recurrence is diagnosed and risk factors for recurrence including histology of the primary tumour.

Aim of the study

The aim of the study incudes assessment of (1) the rate of recurrence of SCT, (2) the time, after which SCT recurrence occurs, (3) pathology or primary and recurrent tumour, (4) how recurrent SCT is diagnosed.

Patients

All patients with SCT treated by each participating centre during a set period of time will be included. Patients with Currarino triad associated SCT are specifically included.

Methods

In a multicenter retrospective SCT data is collected from consecutive patients with SCT. These data are provided by participating centres and collected in an anonymous data base. Assessed are gender, year of birth, age at operation, type of SCT, Currarino association, primary pathology, initial treatment, age at latest follow-up, and if applicable, age at recurrence, method of diagnosis, pathology, and biomarkers (AFP), age and cause of death. Data is collected in a 'tailor made' Castor database. Age is calculated the participating centre by subtracting different dates for which a google website link is provided. Therefore identifiable information such as date of birth and date of any specific procedures are excluded, and anonymization can be maintained.

Participating centers confirm their participation, the inclusion of consecutive patients in a set period of time and sign a data transfer agreement form which defines data ownership, data use, protection and storage of data and authorships.

Analysis

The period of time in which recurrence occurs is assessed in the whole group, with Currarino patients as a predefined subgroup. The risk or recurrence and malignant transformation is assessed with Kaplan-Meyer tests in which is censored for resection. The sensitivity and specificity (if possible) for biomarkers, radiological investigations (ultrasound and MRI), and clinical examination is determined for both benign and malignant recurrence.

Publications

Results will be published in one or more manuscripts. All centres that include ten or more datasets are entitled to name a group author collaborator of the sacrcoccygeal teratoma study group with Medline citation. If more than 50 datasets are included, two group authors may be named.