

Title: First international registry on chronic thromboembolic pulmonary hypertension (CTEPH)

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Body: CTEPH is an uncommon and poorly explored complication of venous thromboembolism. To improve diagnosis and prognosis, physicians belonging to European expert centers strongly involved in the medical-surgical management of CTEPH founded the Association for Research in CTEPH. Research is conducted independently of the funding source. The Association's first project is an international, prospective, observational registry to identify risk factors, characterize CTEPH history, determine time to diagnosis, evaluate long-term survival, predictive factors, and surgical versus medical treatment effects, characterize referral patterns, decision making and pulmonary endarterectomy (PEA) outcomes.

Newly diagnosed, consecutive patients with CTEPH are entered within 6 months of diagnosis into a web-based database. Medical history, clinical status, hemodynamics, imaging and treatment are collected at inclusion and at each patient visit. Statistical procedures are exploratory, including survival analyses and multiple logistic regression. Subgroups of interest for PEA are operable versus non-operable patients for risk factor analysis, and operated versus non-operated for survival analyses. Patient inclusion started in Feb. 2007 and is planned until the end of 2008 or until at least 500 patients have been included. The observation period will be at least 2 years per patient. As of Feb. 2008, data from over 250 subjects have been collected from 18 of the 42 registered sites in 20 European countries and Canada.