

Press Release

Frankfurt, 26 February 2021

Clinical Trial Network for Primary Ciliary Dyskinesia established

The clinical trial network for primary ciliary dyskinesia (PCD-CTN) was founded in 2020 under the framework of the European Reference Network for rare lung diseases (ERN-LUNG) aiming to improve clinical and translational research and facilitate development of new treatments in the field of PCD. This disease-specific CTN initially consists of 18 clinical trial sites in 12 countries in Europe and the United Kingdom and includes over 1100 adult and over 1100 paediatric individuals with PCD so far. The PCD-CTN is headed by a coordinating centre and will be equipped with a steering and executive committee, a data safety monitoring board as well as committees for protocol review, training and standardization. A strong association with patient organizations and industrial companies will be further cornerstones for this newly established PCD-CTN, with the aim to gain evidence-based treatment and knowledge about management for this orphan disease and bring new personalized treatment approaches to the patients.

For more information, please contact the Chair Prof. Kim Nielsen (Kim.G.Nielsen@regionh.dk).