



Impact of a rare respiratory diseases reference centre set-up on primary ciliary dyskinesia care pathway

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This study shows that the creation of the Rare Lung Diseases Centre impacted the PCD patient care pathway with an increase in physiotherapist and paediatric pulmonology consultations, and a decrease of emergency department visits <https://bit.ly/3BfsVWr>

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To the Editor:

Rare diseases have such a low prevalence that special organisation of the patient care pathway is required to address them. In France, the implementation of specific cystic fibrosis (CF) centres [1] has improved the care pathway of CF patients. Indeed, early diagnosis and progress in usual routine treatment might have contributed to improving the prognosis of CF [2]. In the light of this success, rare respiratory diseases reference centres (CRMR: “centre de Références des Maladies Respiratoires Rares”) were created from 2007 under the framework of the national plan for rare diseases. The ear, nose and throat (ENT), pneumology and paediatrics departments at our hospital (CHIC: “Centre hospitalier intercommunal de Créteil”) have a long-standing expertise in the diagnosis and treatment of primary ciliary dyskinesia (PCD) [3, 4]. A reference centre for rare respiratory diseases (CRMR-RESPIRARE-Site Créteil) was accredited in 2017.