



Genetic Disorders of Mucociliary Clearance Consortium (GDMCC)

consortiapedia.fastercures.org/consortia/gdmcc/

Research Areas



Tool Development



Product Development

Drugs

At a Glance

- Status: **Active Consortium**
- Year Launched: **2014**
- Initiating Organization: **NIH Rare Disease Clinical Research Network**
- Initiator Type: **Government**
- **Rare disease**
- Location: **International**

Abstract

The Genetic Disorders of Mucociliary Clearance Consortium (GDMCC) exists to bring together physicians and patients for the sake of mucociliary clearance diseases research. Research offers no guarantees, but research cannot move forward without the help of patients. Every active role a patient takes may possibly play a part in discovering new groundbreaking research and finding new treatments.

Mission

The mission of the GDMCC is to create and maintain a clinical research network to study rare diseases of the airways, focusing on primary ciliary dyskinesia (PCD), nontuberculous mycobacteria (NTM) pulmonary disease, and idiopathic bronchiectasis with rigorous diagnostic evaluations and comparative clinical studies in cystic fibrosis (CF), pseudohypoaldosteronism (PHA), and other chronic airway disease.



The goals of this consortium is are as follows:

Structure & Governance

This consortium is part of the Rare Diseases Clinical Research Network (RDCRN), an initiative of the Office of Rare Diseases Research, National Center for Advancing Translational Sciences (NCATS). The RDCRN is designed to advance medical research on rare diseases by providing support for clinical studies and facilitating collaboration, study enrollment, and data sharing. Through the RDCRN consortia, physician scientists, and their multidisciplinary teams work together with patient advocacy groups to study more than 200 rare diseases at sites across the nation.

Funding and scientific oversight for the RDCRN are provided by NCATS and 10 National Institutes of Health components: Eunice Kennedy Shriver National Institute of Child Health and Human Development; National Cancer Institute; National Heart, Lung and Blood Institute; National Institute of Allergy and Infectious Diseases; National Institute of Arthritis and Musculoskeletal and Skin Diseases; National Institute of Dental and Craniofacial Research; National Institute of Diabetes and Digestive and Kidney Diseases; National Institute of Mental Health; National Institute of Neurological Disorders and Stroke; and Office of the Director. In addition, patient advocacy groups provide funds for many of the projects.

Patent Engagement

The GDMCC Patient Contact Registry is a method by which patients (and their families) with mucociliary clearance disorders can register themselves to be contacted in the future about clinical research opportunities. An online registry form exists for all the GDMCC diseases currently being studied: (a) Primary Ciliary Dyskinesia (PCD), (b) Cystic Fibrosis, and (c) Pseudohypoaldosteronism (PHA).

Links/Social Media Feed

Homepage

<http://www.rarediseasesnetwork.org/GDMCC/index.htm>



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Updated: 04/18/2016