The Bronchiectasis Research Registry: A Resource for Collaborative Research in non-Cystic Fibrosis Bronchiectasis

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Introduction

Bronchiectasis is characterized by inflamed bronchi that are abnormally dilated and chronically infected. Significant morbidity and mortality are associated with this progressive disease that affects thousands of patients.

The Bronchiectasis Research Registry was designed to support collaborative research and assist in the planning of future therapeutic clinical trials with the overarching goals of improving patient management and furthering our understanding of the diagnosis and pathophysiology of the disease.

Methods

The Bronchiectasis Research Registry is a consolidated database of non-cystic fibrosis patients from major clinical and research institutions (n=10) across the US. The Registry was established by the Bronchiectasis Research Consortium, is funded by the COPD Foundation, and is governed by the Registry Advisory Board.

The Coordinating Center (CC), located at the University of North Carolina in Chapel Hill, developed and maintains a secure, web-based data management (DMS) and interactive reporting system for the collection, processing, storage, and analysis of data.

Adult bronchiectasis patients are asked to participate and consent to (1) use of their data for research purposes and (2) future contacts concerning participation in clinical trials.

Data acquisition is conducted through medical records abstraction and/or clinic examination and includes demographics; medical history; and clinical procedures pertinent to the treatment of bronchiectasis, namely respiratory symptoms, pulmonary function testing, lung imaging, diagnostic tests, and therapies.

The interactive reporting system provides Consortium investigators with user-friendly, real-time access (24-hour currency) to both standard and custom analyses of Registry data.

Results

Data collection began in Fall 2008. To date, 500 patients have been enrolled from 9 centers, and 93% have consented to future contacts. Ninety-two % of expected data collection forms have been entered into the DMS, with complete data obtained for 78% of participants.

Annual follow-up data collection began in Spring 2010 to update contact information and clinical data, including health status, clinical endpoints, respiratory symptoms, therapies, clinical procedures (lung functions) and laboratory microbiology.

Future Plans

Future plans include expanding recruitment to additional clinical centers, linking to stored image data for central reading, and expanding the DMS to incorporate the transfer of existing electronic medical records from clinical centers.