The Bronchiectasis Research Registry
Clinical, Microbiologic, and Treatment Characteristics

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Introduction
A consortium of US academic institutions supported by the COPD Foundation created the Bronchiectasis Research Registry as a consolidated database of non-cystic fibrosis bronchiectasis patients. The overarching goal of this registry is to support collaborative research and facilitate future therapeutic clinical trials in bronchiectasis. Other aims for the registry include:

- Demonstrate patterns of bronchiectasis patient characteristics by obtaining pertinent background information concerning rates of concomitant illnesses, medications, or other disease related information.
- Facilitate planning of therapeutic clinical trials by generating lists of patients who satisfy inclusion/exclusion criteria.

Background
Non-cystic fibrosis bronchiectasis is a progressive, non-curable disease of the lungs. It is characterized by inflamed or abnormally dilated thick walled bronchi and chronic pulmonary bacterial infections, and is associated with significant morbidity and mortality. This comprehensive patient registry may be of interest to researchers interested in conducting exploratory or hypothesis-generating research to examine etiologies of bronchiectasis.

Materials and Methods
- The Registry, maintained by the Collaborative Studies Coordinating Center at UNC in Chapel Hill, consists of a secure, web-based data management and interactive reporting system for the collection, processing, storage, and analysis of data.
- Using the Registry’s standard and custom reporting features, the data base was queried for demographic and clinical variables that may be of interest for clinical trial enrollment criteria.
- Clinical information was available for standard query on 484 patients.
- Standard reports are always available, and content is updated nightly to reflect registry enrollment as of the previous day. User generated reports are based on specified combinations of variables, graph types, and restrictions.

Summary/ Limitations
This bronchiectasis patient population represents an ideal source for evaluation of new therapies. These patients:
- Suffer from high rates of pulmonary symptoms
- Have high frequencies of bacterial and mycobacterial infection
- Are currently using pharmaceutical and non-pharmaceutical therapeutic measures for disease management.

Limitations:
- This population may not be fully representative of the general U.S bronchiectasis population because the sample is biased towards more severe disease and referral bias of participating institutions.

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Results and Figures

Overall Pulmonary Function: FVC % Predicted

Overall Pulmonary Function: FEV1 % Predicted

Results of Most Recent Bacterial Culture

Nontuberculous Mycobacterial Species Distribution Among "Active with NTM" culture positive patients

Age Distribution by NTM Culture Status

Patients With Each Type of Therapy

Nasal Nitric Oxide