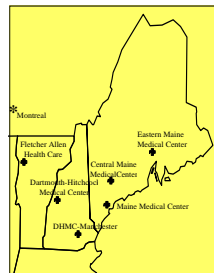


# Variability in Rates of FEV<sub>1</sub> Decline Across Cystic Fibrosis Centers in the United States

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## The Northern New England Cystic Fibrosis Consortium



The NNECFC is a regional, voluntary consortium of more than 80 clinicians and researchers from the CF care centers in Maine, New Hampshire and Vermont.

The mission of the group is to improve CF care and patient outcomes.

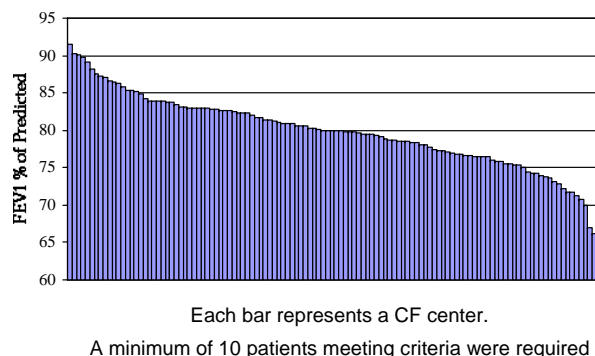
## Goals

- Characterize variation in mean baseline FEV<sub>1</sub> percent predicted and differences in annual mean FEV<sub>1</sub> decline rates between CF centers in the United States.

## Methods

- Dataset consisted of 14,429 patients from the US CFF Registry from 1991-2000 (95,813 FEV<sub>1</sub> measures).
- Patients 6 to 24 years with at least 3 annual measures of FEV<sub>1</sub> were included. Transplant patients were removed.
- Generalized estimating equations were used for baseline FEV<sub>1</sub> and annual decline rates.
- Data were case-mix adjusted for differences in baseline patient characteristics: sex, age at diagnosis, genotype, race, presentation, income.

## Variation in FEV<sub>1</sub> at Age 6 by Center p<0.0001

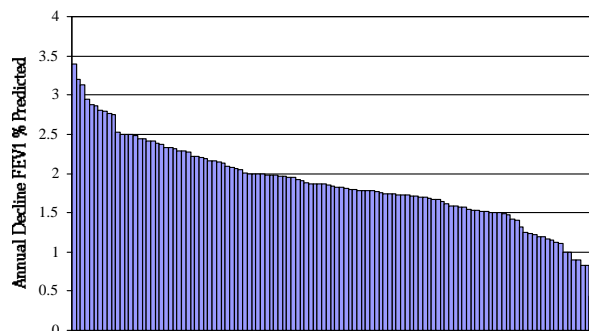


## Results

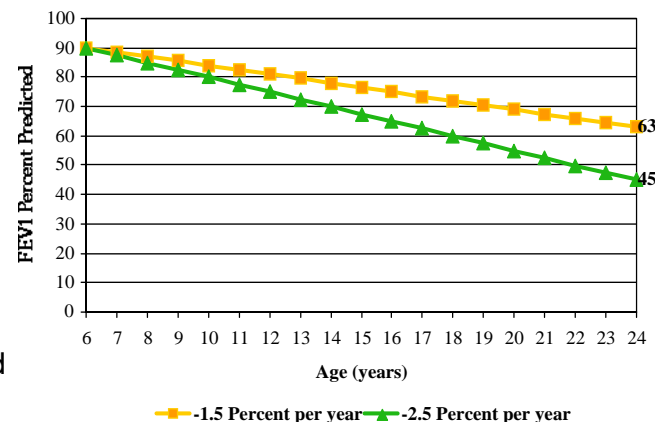
Statistically significant differences were found between centers in these case-mix adjusted data:

- Range of FEV<sub>1</sub> at age 6 by center = **66% - 92%**
- 5th - 95th percentile range of FEV<sub>1</sub> annual decline by center = **1.0% - 2.8%**

## Variation in FEV<sub>1</sub> Decline by Center p<0.0001



## FEV<sub>1</sub> at Age 24 Based on 1.5% vs. 2.5% Annual Decline Rate



## Conclusions

- Baseline FEV<sub>1</sub> rates at age 6 vary significantly between centers even after case-mix adjustment.
- These case-mix adjusted data indicate significant variation in FEV<sub>1</sub> decline rate across CF centers.
- Even after adjustment for baseline patient and disease characteristics there was almost a three-fold difference between the 5th and 95th percentile rates of decline.
- Further study of differences in treatments used, practice variation, and local environmental conditions will be important to understand the etiology of these differences.