

## At a Glance:

### The Cystic Fibrosis Foundation's Unique and Successful Business Model

- Life expectancy for people with CF has more than doubled in the past 25 years to age 37.4. This progress is the result of dramatic advances in research and care, fueled by the Cystic Fibrosis Foundation.
- A critical component of this success is the Cystic Fibrosis Foundation's unique business model, which applies the same results-driven approach of success as a "for-profit" company.
- The business model is based on a concept known as "venture philanthropy" – a growing business practice for charitable organizations that involves funding drug research with for-profit companies for the purpose of finding a cure for a rare disease. The Foundation is considered the national leader in venture philanthropy.
- This business model has yielded dozens of collaborations with leading biotech companies and a drug development pipeline with more than 30 promising therapies. Since 1998, the Foundation and its nonprofit affiliate Cystic Fibrosis Foundation Therapeutics, Inc., (CFFT) have committed more than \$320 million for promising scientific research with biotech firms.
- The Foundation invests more money in drug development with biotech firms than any other disease foundation in the country, according to *CenterWatch Monthly*, an industry trade publication.
- The Foundation's business model has been featured in some of the nation's most prestigious media outlets, including *Forbes*, *BusinessWeek*, *The Boston Globe* and *National Public Radio*. It has been recognized by the National Institutes of Health, emulated by a growing number of nonprofits and is the subject of two Harvard Business School case studies.
- For the first time in the history of the disease, the CF pipeline has therapies under development that target the root cause of cystic fibrosis, rather than just the symptoms. If successful, these therapies will add decades of life for people with CF.
- One compound being developed by Vertex Pharmaceuticals, known as VX-770, demonstrated groundbreaking early results in the spring of 2008 in Phase 2a clinical trials. The compound showed that it could actually fix the biochemical flaw in some CF patients.
- Virtually every approved CF drug available today was made possible because of support from the Foundation and its nonprofit affiliate, CFFT. Since the 1980s, the Foundation and CFFT have played an integral role in the development of Pulmozyme<sup>®</sup>, TOBI<sup>®</sup>, azithromycin and hypertonic saline for use as CF treatments.

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