A Care Model for Cystic Fibrosis

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People with CF do best when:

• They have highly individualized treatment
• They can balance their treatments with daily life
• Their care plans address the whole person—physical, mental and social
“We count our successes in lives.”

From 1996 to 2017, the median predicted survival age for people with CF increased more than 11 years—from 32.3 years to 43.6 years.

Diagnosing CF is a multistep process

Most children are now screened for CF at birth through newborn screening and the majority are diagnosed by age 2.

https://www.cff.org/What-is-CF/Diagnosed-With-Cystic-Fibrosis/
Coordinated, multidisciplinary teams

We provide funding for and accredit more than 130 CF care centers nationwide.

More than 30,000 people with CF were seen by an accredited care center in 2018, representing more than 90% of the CF population in the U.S.

[Image: https://www.cff.org/Care/Care-Centers/]
“Data is for improvement, not judgement.”

Bruce Marshall, SVP Clinical Affairs

Establishing the Registry in 1966 was a visionary step by our founding families, laying the groundwork for research and care improvements that have added decades of life for people with CF.

https://www.cff.org/Care/Clinician-Resources/Clinician-Awards/
What is Best Care: “care based on the best available evidence, takes appropriate account of individual preferences, and is delivered reliably and efficiently”

Three imperatives for achieving a continuously learning health care system:

• Managing rapidly increasing complexity
• Achieving greater value in health care
• Capturing opportunities from technology, industry, and policy

Learning Health System
Moving towards a continuously learning health care system

FIGURE S-2 Schematic of the health care system today.

FIGURE S-3 Schematic of the continuously learning health care system.
What is a Learning Network?
• Community of patients, families, clinicians, and scientists across multiple sites who use data for clinical care, improvement, discovery (research) and innovation

Why Learning Networks?
• Reliable improvement in population outcomes at scale
• Culture of collaboration that engages all stakeholders
• Useful laboratories
• Provide a robust infrastructure to produce new knowledge and innovative care models
Examples: Improved Outcomes in Learning Networks
Thank you
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