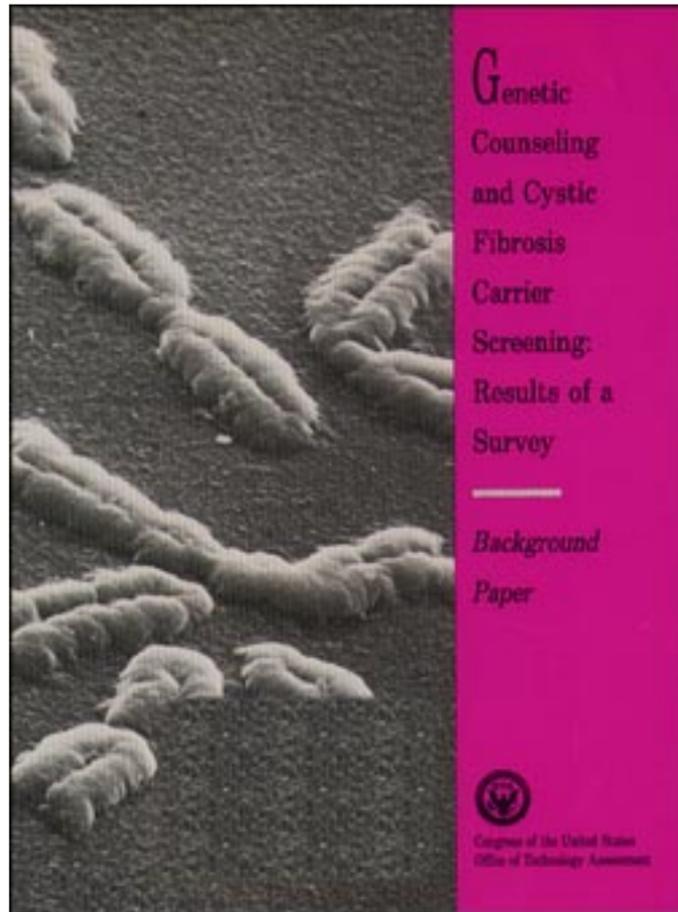


*Genetic Counseling and Cystic Fibrosis
Carrier Screening: Results of a Survey*

October 1992

OTA-BP-BA-97

NTIS order #PB93-101764



Recommended Citation:

U.S. Congress, Office of Technology Assessment, *Genetic Counseling and Cystic Fibrosis Carrier Screening: Results of a Survey--Background Paper, OTA-BP-BA-97* (Washington, DC: U.S. Government Printing Office, September 1992).

For sale by the U.S. Government Printing Office
Superintendent of Documents, Mail Stop: SSOP, Washington, DC 20402-9328

ISBN 0-16-038093-6

Foreword

For years, experts have theorized about the consequences of increased knowledge of human genetics. In the early 1990s, development of a DNA-based test to identify carriers of cystic fibrosis (CF) moved the debate from the theoretical to the practical. The CF carrier assay is but one of many tests to come that will place genetic counselors and nurses working in genetics at the front line on the issues raised by assimilation of DNA tests into clinical practice.

This OTA Background Paper presents results from a 1991 OTA survey of 431 genetic counselors and nurse geneticists. It was conducted to better understand the environment in which the average genetic counselor or nurse in genetics works, to describe the infrastructure and tools available to these professionals, to assess the state of practice in the provision of CF carrier screening, and to evaluate their attitudes regarding CF carrier screening. The survey supports OTA's August 1992 assessment *Cystic Fibrosis and DNA Tests: Implications of Carrier Screening*; the full assessment was requested by the House Committee on Science, Space, and Technology, the House Committee on Energy and Commerce, and Representative David R. Obey.

The survey data collected by OTA reflect the tensions and concerns surrounding the widespread implementation of CF carrier screening. Those who currently oppose routine carrier screening for CF raise concerns about the sensitivity of the test, the numbers of individuals that would be potentially screened—and the subsequent effect on the clinical genetics infrastructure--and the possibilities of stigma, discrimination, and poor quality in services. Those who think CF carrier screening should be widely available believe the information provided by the test increases patient autonomy and lowers uncertainty regarding reproductive futures.

OTA was assisted in preparing the survey instrument and Background Paper by a panel of advisors, contractors, workshop participants, and reviewers selected for their expertise and diverse points of view. We gratefully acknowledge the contribution of each of these individuals. OTA, however, remains solely responsible for the contents of this Background Paper.


JOHN H. GIBBONS
Director

LIBRARY
OFFICE OF TECHNOLOGY ASSESSMENT
CONGRESS OF THE UNITED STATES
10/5/92

Cystic Fibrosis and DNA Tests: Implications of Carrier Screening Advisory Panel

Jessica G. Davis, *Panel Chair*
Co-Director, Division of Human Genetics
New York Hospital
Cornell University Medical College
New York, NY

Arthur L. Beaudet
Professor
Howard Hughes Medical Institute
Baylor College of Medicine
Houston, TX

Debra L. Collins
Genetic Counselor
University of Kansas Medical Center
Kansas City, KS

Beth A. Fine
Genetic Counselor/Clinical Instructor
Northwestern University Medical School
Chicago, IL

Lynn D. Fleisher
Attorney
Sidley & Austin
Chicago, IL

Clark C. Havighurst
William Neal Reynolds Professor of Law
Duke University School of Law
Durham, NC

John Z. Jacoby, III
Clinical Assistant
The Cystic Fibrosis Center
St. Vincent's Hospital and Medical Center
New York, NY

Angèle Khachadour
General Counsel
Hastings College of the Law
San Francisco, CA

Katherine W. Klinger
Vice President, Science
Integrated Genetics
Framingham, MA

Arthur Lifson
Vice President
CIGNA Companies
Hartford, CT

Robert F. Murray, Jr.
Professor
Department of Pediatrics and Child Health
Howard University School of Medicine
Washington, DC

Mark V. Pauly
Executive Director
Leonard Davis Institute of Health Economics
University of Pennsylvania
Philadelphia, PA

Susan Poling
Parent
Silver Spring, MD

Thomas K. Reed, Jr.
chairman
Vivigen, Inc.
Santa Fe, NM

Philip R. Reilly
President
Shriver Center for Mental Retardation, Inc.
Waltham, MA

Joseph D. Schulman
Director
Genetics & IVF Institute
Fairfax, VA

NOTE: OTA is grateful for the valuable assistance and thoughtful critiques provided by the advisory panel members. The panel does not, however, necessarily approve, disapprove, or endorse this report. OTA assumes full responsibility for the report and the accuracy of its contents.

Genetic Counseling and Cystic Fibrosis Carrier Screening: Results of a Survey OTA Project Staff

Roger C. Herdman, Assistant Director, OTA Health and Life Sciences Division

Michael Gough, Biological Applications Program Manager

Robyn Y. Nishimi, Project Director

Kathi E. Hanna, *Study Director*

Ellen L. Goode, Research Analyst

Margaret A. Anderson, Analyst¹ and Contractor

Sheryl M. Winston, Research Analyst

Administrative Staff

Cécile Parker, *Office Administrator*

Linda Rayford-Journiette, *PC Specialist*

Jene Lewis, *Administrative Secretary*

Contractors

Gary B. Ellis, *Editor*, Silver Spring, MD

John M. Boyle, Schulman, Ronca & Bucuvalas, Inc., Silver Spring, MD

Ferdinand J. Chabot, Newton, IA

Bob Jones, IV, Arlington, VA

Ann C.M. Smith, Reston, VA