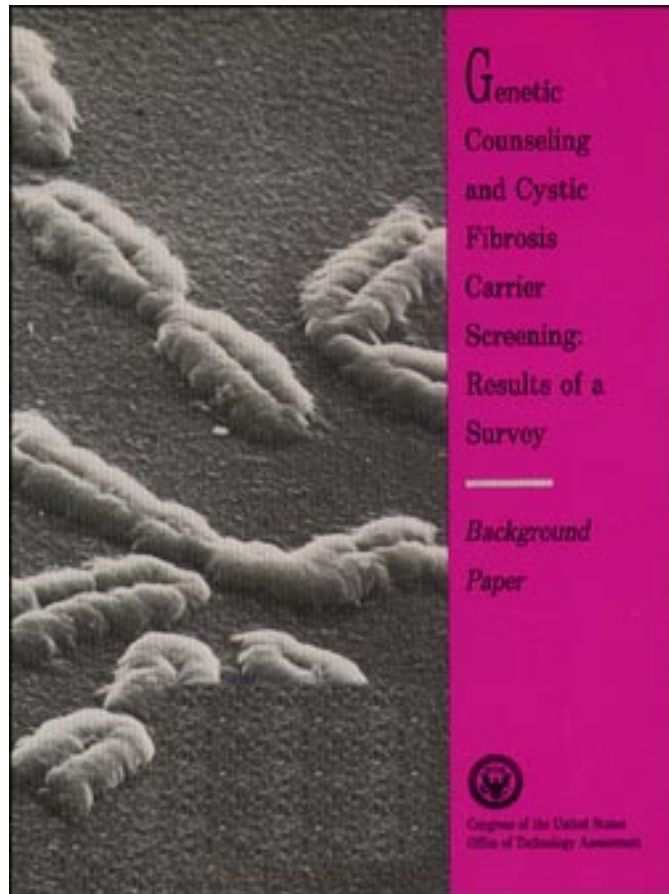


*Genetic Counseling and Cystic Fibrosis  
Carrier Screening: Results of a Survey*

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# 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.



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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.

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