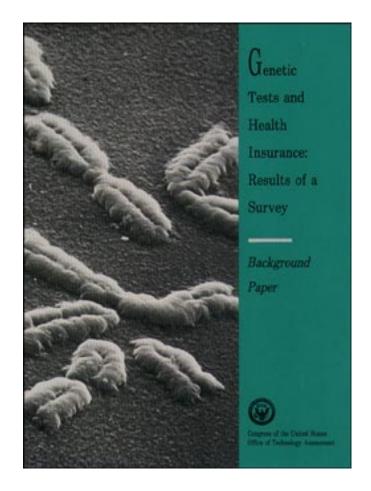
Genetic Tests and Health Insurance: Results of a Survey

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Foreword

As we increase our knowledge of human genetic diseases and improve our ability to diagnose and predict them, concern about denial or restriction of health care insurance is often raised. Yet little is known about either health insurers' attitudes toward reimbursement for genetic tests or policies for using test results in underwriting. To assess these views and practices, OTA surveyed commercial insurers, Blue Cross and Blue Shield plans, and health maintenance organizations that offer individual or medically underwritten group policies.

OTA undertook the survey in support of its assessment *Cystic Fibrosis and DNA Tests: Implications of Carrier Screening*, which was published in August 1992. That report—requested by the House Committee on Science, Space, and Technology, the House Committee on Energy and Commerce, and Representative David R. Obey—focuses on survey results specific to cystic fibrosis carrier screening. This background paper summarizes information about cystic-fibrosis and presents additional results that pertain to the broader topic of health insurers' practices and attitudes toward genetic information and genetic tests for diseases other than cystic fibrosis. It presents survey findings related to:

- . how health insurers view information from various sources+. g., genetic tests, other medical tests, or family histories-in underwriting decisions;
- . current and future policies toward reimbursing consumers for the costs of genetic tests; and
- . expectations about the impact and use of genetic tests and genetic information on health insurance.

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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¹Through December 1991