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# INTRODUCTION

## Understanding the Role of Genetics in Disability Insurance

*Jeffrey P. Kahn and Susan M. Wolf*

This collection of articles represents the product of a project funded by the National Institutes of Health (NIH) to produce the first in-depth analysis of the role of genetic testing in disability insurance. A national Working Group comprised of diverse experts met over the course of two years, performing an extensive review of the available disability insurance literature, analyzing disability insurance policies, and sponsoring a day-long symposium at which Working Group members and other speakers presented their analyses of genetic testing's implications for disability insurance and for the concept of disability more broadly. The collection found here in this supplementary issue of the *Journal of Law, Medicine & Ethics* includes (1) the project report, presenting conclusions and policy recommendations informed by input from the Working Group; (2) a minority commentary to the report authored by two members of the Working Group; and (3) articles focusing on a range of issues related to genetic testing and disability insurance, which originated as presentations at the symposium.

Working Group members represented a wide range of expertise – ethics, law, public policy, and medicine – from academia and the insurance industry. Additional invited speakers for the symposium included academic experts and a Commissioner of the Equal Employment Opportunity Commission (EEOC).

The articles are organized to provide a flow of perspectives. The report authored by the co-leaders of the Working Group begins the collection, explains the issues identified and analyzed by the Working Group, and offers recommendations. After the report, a commentary authored by two Working Group members from the insurance industry, John Dodge and David Christianson, presents a different perspective on the

issues. Their two individually authored articles follow, one explaining the process of medical underwriting, and the other the impact of genetic testing on the private insurance market. Next is Paul Miller's commentary, examining the concept of disability in the age of genetics from his perspective as then-Commissioner of the EEOC. Anita Silvers's article follows, arguing that insurers and the public share an interest in policies for dealing with predictive genetic testing in the context of insurance. Next, Mark Rothstein offers an argument against so-called genetic exceptionalism, while acknowledging that genetics-specific legislation is warranted under some circumstances. Nancy Kass and Amy Medley's article then examines how we can learn from the debate over genetic information in the context of health insurance. Kathryn Sedo presents an analysis of the impact of genetic testing on Worker's Compensation and public disability programs. Finally, Robert Jerry examines the relationship among life, health, and disability insurance and offers policy recommendations for addressing the use of genetic information in disability insurance.

Together, the report, commentary, and articles present the first comprehensive examination of the issues raised by genetic testing in the context of disability insurance. Our hope is that they will help illuminate this complex set of issues and inform the debate over how to address the increasingly important insurance challenges posed by genetic testing.

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**Jeffrey P. Kahn, Ph.D., M.P.H.**, is the Maas Family Chair in Bioethics and Professor of Medicine at the University of Minnesota. He is Director of the University's Center for Bioethics. **Susan M. Wolf, J.D.**, is the McKnight Presidential Professor of Law, Medicine & Public Policy; Faegre & Benson Professor of Law; and Professor of Medicine at the University of Minnesota. She is Chair of the University of Minnesota's Consortium on Law and Values in Health, Environment & the Life Sciences and Director of the University's Joint Degree Program in Law, Health & the Life Sciences.