THE GENETIC INFORMATION NONDISCRIMINATION ACT: A NEW LOOK AT AN OLD PROBLEM

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ABSTRACT

Following more than a decade of congressional and academic debate, the Genetic Information Nondiscrimination Act of 2008 (GINA) was signed into law. GINA forbids health insurers from making coverage determinations based on genetic information from a broad range of sources. GINA has put an end to a patchwork of inconsistent state and federal laws regulating the use of genetic information by the health insurance industry. This essay offers a new framework for understanding the merits of GINA and the appropriateness of its scope. Drawing on economic rationales, this essay shows that genetics legislation pre-GINA failed to adequately advance the principle policy objectives genetic nondiscrimination laws had claimed to serve, i.e., protecting the confidentiality of sensitive genetic test results, and maximizing the social and economic value of genetic research.

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TABLE OF CONTENTS

I. Introduction ....................................................................................... 3

II. The Use of Genetic Information by Health Insurers ....................... 5
   A. Sources of Genetic Information.................................................... 5
   B. Genetic Information: The Competing Interests............................ 7
      1. The Benefits of Genetic Information for the Individual.......... 7
      2. The Social Benefits of Genetic Information.............................. 8
      3. Genetic Information and the Health Insurance Industry........... 8
   C. Arguments For and Against the Use of Genetic Information by
      the Health Insurance Industry................................................... 10
      1. Effect of Genetic Information on Insurability........................ 10
      2. Genes are Beyond One’s Control............................................ 11
      3. Misunderstanding Genetic Information................................... 11
      4. Privacy..................................................................................... 12
   D. Laws Prohibiting the Use of Genetic Information by the Health
      Insurance Industry..................................................................... 13
      2. The Health Insurance Portability and Accountability Act ...... 15
      3. State Genetic Nondiscrimination Laws ................................... 16
   E. Actual Use of Family Medical Information by the Health
      Insurance Industry..................................................................... 17

III. Is Family Medical History Different? An Economic Analysis .... 18
   A. Principles of the Economics of Information............................... 18
   B. Genetic Testing versus Family Medical History: Does the
      Difference Make a Difference?.................................................... 20
   C. Tracing the Family Medical History: The True Picture ............ 22
   D. Encouraging the Search for Family Health History............... 23

VI. The Demise of the Genetic Test Results/Family History Distinction
............................................................................................................ 25
   A. Can the Distinction Between Genetic Test Results and Family
      Medical History be Sustained? .................................................... 25
   B. Unraveling the Unraveling Problem.......................................... 28

V. Conclusion ..................................................................................... 30
I. INTRODUCTION

Following more than a decade of continuous academic and congressional debate, congress has finally settled the issue of health insurers’ access to genetic information by adopting the Genetic Information Nondiscrimination Act of 2008 (GINA).\(^1\) GINA provides comprehensive protection, outlawing the use of genetic information by health insurers when making coverage determinations. Unlike previous genetic nondiscrimination laws, GINA’s definition of “genetic information” is all-embracing, and encompasses a wide spectrum of medical data that can indicate an individual’s predisposition towards a particular illness. One of the central changes established by GINA is an across-the-board prohibition of the use of family health history by the health insurance industry.

This essay offers a new framework for understanding the merits of GINA and the appropriateness of its scope. Drawing on economic rationales, the essay explains why GINA’s extensive prohibition of the use of family medical history by health insurers represents a substantial improvement over the preexisting legislative scheme, which largely left family medical information unprotected. It examines the nexus between family medical history and other innovative sources of genetic information, and shows that the former exclusion of family medical information from legal protection had considerably impeded the effectiveness of genetics legislation.

The past few years have been marked by significant progress in understanding the role of genetic factors in human health and disease. Scientific and technological advancements in genetics have made possible increasingly accurate statistical predictions about an individual’s future health risks.

As innovative genetic technology has become increasingly ingrained in medicine, health insurers’ access to genetic information has sparked major concerns. In the wake of public fear that utilization of genetic services will adversely affect health insurability, statutes banning the use of genetic information by the health insurance industry have been enacted at both the state and federal levels. Yet, no consensus has evolved on the statutory definition of genetic information.

State laws have adopted conflicting approaches. Some legislators defined the term “genetic information” narrowly, only prohibiting the use of innovative laboratory techniques that can detect inheritable characteristics (“genetic testing.”) Other legislators used a more comprehensive definition, also banning the use of genetic information derived from sources that have been an integral part of the underwriting process for generations, such as family medical history.

Splitting genetic information into two categories has been repeatedly criticized by commentators, who often called for comprehensive and uniform protection against health insurers’ access to genetic information. Yet, while those who tried to confront the definitional dilemma typically agree that the traditional family medical history is genetic in nature, they have treated it as simply another piece of genetic information. The distinctive features of family medical information and its contemporary role in medical genetics have been largely overlooked by legal academics. This omission was troubling, as it contributed to an incomplete understanding of the social and economic dynamics underlying the regulation of genetic information in the area of health insurance.

GINA has proscribed health insurers in both the individual and group markets from making coverage determinations based solely on individuals’ genetic predisposition to develop a future disease. GINA’s scope of protection is remarkably broad. In addition to outlawing health insurers’ access to a wide variety of predictive genetic tests, GINA places a wide spectrum of family medical information off-limits. Family health information protected under GINA includes information about the genetic tests of family members, the manifestation of disease or disorder in family members, information about any fetus carried by a pregnant woman and any embryo held by the individual or family members. GINA’s definition of “family members” covers up to fourth-degree relatives.

This essay argues that by filling the family history gap, GINA has effectively cured some of the major deficiencies in the prior genetic legislative fabric. As this essay shall show, the limited protection previously provided to family health information undercut the principle policy objectives genetic legislation claimed to serve, i.e., protecting the confidentiality of sensitive genetic test results, and maximizing the social and economic value of genetic research.

Part II provides necessary background information about the various sources of genetic information and their value to the health insurance industry. It also reviews the arguments that have been made by scholars for and against legislation prohibiting the use of genetic information by health insurers, and the laws that were enacted in the wake of this debate. The discussion demonstrates

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that prior to the enactment of GINA, genetic information derived from family health history was largely left unprotected.

Part III shows that privileging innovative genetic testing, while leaving traditional family medical information unprotected, is at odds with notions of economic efficiency. The discussion draws attention to the prominent role of family history in medical genetics, and the extensive amount of family health information that is required for a reliable interpretation of genetic testing. These aspects have received little legal attention. Part III concludes that banning the use of family health history by the health insurance industry is a key component in the effort to realize the full potential of genetic research.

Part IV shows that even if drawing a sharp line between family medical history and genetic testing is defensible, it is virtually impossible. Having a hereditary disease in the family does not provide conclusive evidence that all family members are carrying the familial “defective genes.” The results of genetic testing can determine an individual family member’s risk for developing that particular genetic condition with greater certainty.

When health insurers are free to use “second best” evidence, i.e., family health history, to assess applicants’ risk, applicants with questionable family history have incentives both to undergo genetic testing, and to disclose favorable results to the insurer, thereby escaping the high-risk pool. Selective disclosure of favorable genetic test results will lead insurers to infer that those who remain silent are withholding unfavorable test results. Paradoxically, even in the absence of direct access to genetic test results, sensitive genetic information is likely to surface. Attempts to protect the confidentiality of sensitive genetic testing without simultaneous protection of family medical history are therefore doomed to fail.

II. The Use of Genetic Information by Health Insurers

A. Sources of Genetic Information

In April 2003, scientists announced the successful completion of the Human Genome Project. Information generated by the Human Genome Project, together with recent development of sophisticated genetic technologies, promises to revolutionize medicine and health care. Understanding the genetic contributions to the risk of diseases may ultimately allow the development of effective strategies for diagnosis, prevention and treatment of diseases. The more insights scientists get into the mysteries of human genes, the more genetic information is expected to be utilized in the practice of medicine.

Genetic information can potentially be derived from many different sources. One major way to attain genetic information is by means of genetic

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3 For background information on the Human Genome Project see National Human Genome Research Institute, All About The Human Genome Project (HGP), http://www.genome.gov/10001772 (last visited Feb. 13, 2009).

4 For a discussion of the various sources of genetic information, see Rich & Ziegler, supra note 1,
testing, which involves a variety of laboratory techniques that analyze biological materials such as DNA, RNA, chromosomes, and proteins. The analysis is conducted in order to identify abnormalities associated with inheritable conditions.

Genetic tests are increasingly becoming an integral feature of health care. At present, there are more than a thousand clinical genetic tests available, and several hundred more are available in a research setting. Genetic testing can help predict risk for a wide range of diseases such as Huntington’s disease, cystic fibrosis, hypercholesterolemia, sickle-cell traits, selected forms of Alzheimer’s disease, colon cancer, melanoma, breast and ovarian cancer. A positive test result for BRCA1 or BRCA2 for example, can indicate that an individual has a greater than average risk of developing breast cancer. Genetic tests can also be utilized to confirm diagnosis of medical conditions, guide treatment of affected individuals, help determine medication dosages and inform reproduction decisions.

Another source of information that can provide hints about one’s genetic profile is the family medical history. A pattern of inheritable illnesses affecting one’s family members may suggest that one is also at risk for developing the particular condition. Family health history is perhaps the most traditional tool used by physicians to identify possible genetic conditions and develop prevention strategies.

Though genetic technology continues to evolve, the traditional family health history still provides a telling source of information in medical genetics.

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5 Gene Tests, available at <http://genetests.org/> (last visited Feb 25, 2009). The precise definition of “genetic testing” is highly debatable and has received extensive scholarly attention. As this essay focuses particularly on genetic information derived from family medical history, elaborating on this issue is beyond its scope.

6 Id.

7 Id.


9 American Cancer Society, What are the Risk Factors for Breast Cancer? (09.18.2006). http://www.cancer.org/docroot/CRI/content/CRI_2_4_2X_What_are_the_risk_factors_for_breast_cancer_5.asp (last visited 5.9.07) [hereinafter RISK FACTORS FOR BREAST CANCER] (“Women with an inherited BRCA1 or BRCA2 mutation have up to an 80% chance of developing breast cancer during their lifetime and at a younger age than those women who are not born with one of these gene mutations in their cells.”)


11 For discussions of the importance of family medical information in medical genetics see
To begin with, the manifestation in the family of a disease that has a genetic basis is often the first “red flag” that other family members have an increased risk for that hereditary condition. Individuals with genetic diseases in their families may therefore be among the most likely candidates for genetic testing.12

Further, and perhaps more importantly, family health information is “a critical factor in determining the value of predictive genetic testing.”13 Despite the increasing sophistication of genetic technology, the results of genetic testing are not always straightforward. Medical genetics and genetic counselors therefore rely on family history for help when interpreting the results of genetic tests.14 For example, in order to make a useful prediction that someone with positive genetic test results for the BCRA1 gene will eventually develop breast cancer, genetic professionals attribute great importance to information about other family members who developed the disease.15

B. Genetic Information: The Competing Interests

As genetic technology has become increasingly ingrained in medicine, the use of genetic information by third parties to predict the onset of a future illness has been the subject of ongoing debate. One particular area of concern is that genetic information will be used by the health insurance industry to determine eligibility and set premiums. In fact, health insurers’ access to genetic information has proven to be fraught with considerable tension and social and economic complications. To truly appreciate the source of tension and its likely implications, one must first understand the competing interests surrounding genetic information.

1. The Benefits of Genetic Information for the Individual

Genetic information may be particularly beneficial for individuals who possess it. Knowing one’s genetic status can be a powerful predictive tool. It might encourage individuals to take steps to reduce their risk through preventive medical care or appropriate lifestyle changes.16 For example, if a woman knows

generally Eugene C. Rich et al., Reconsidering the Family History in Primary Care, 19 J. OF GENERAL INTERNAL MEDICINE 273 (2004); Alan E. Guttmacher et al., The Family History: More Important Than Ever, 351 N. ENGL. J. MED., 2333 (2004); Monica Alvarado et al., Genetic Services in the KP Southern California Region: Delivering the Promises of Tomorrow Today, 10 PERMANENTE J., 29, 35 (2006).

12 Rich et al., id. at 274 (“People at increased risk because of their family history may be among the most appropriate candidates for genetic tests.”)

13 Id. at 276.

14 Id. at 274-76 (discussing the primary role family history plays in evaluating the predictive value of genetic test results). See also Alvarado et al., note 11, at 35.

15 Margaret M. Eberl et al., Patients with a Family History of Cancer: Identification and Management, 18 J. OF THE AMERICAN BOARD OF FAMILY PRACTICE 211, 211 (2005) (“Family histories of cancer that suggest increased susceptibility include: two or more relatives on the same side of the family with the same or a related cancer, earlier than average age of diagnosis [typically 50 years of age for most cancers], and the presence of more than one primary cancer in a family member, exclusive of metastatic disease.”)

16 Eric M. Holmes, Solving the Insurance/Genetic Fair/Unfair Discrimination Dilemma in Light
that she carries a gene associated with breast cancer, that might be an incentive to have periodic screening tests, and to avoid behaviors that trigger the disease, such as high alcohol consumption, eating red meat, and lack of physical activity. Even when a cure is not available, or it is otherwise impossible to lessen the risk through preventive strategies, individuals are still likely to derive benefit from genetic information. Genetic self-knowledge might, for instance, empower individuals and family members to make informed choices in reproduction, it might influence mating and career decisions, or otherwise allow individuals to plan their lives accordingly.

2. The Social Benefits of Genetic Information

Broad utilization of genetic technologies can also serve the general social welfare in the form of health promotion. Wide acceptance of genetic technologies, and implementation of public health screening programs could potentially mean early detection of diseases, better diagnostic tools, and treatments that are more effective. Such medical advances could eventually translate into a healthier public, and – one hopes – reduce total healthcare expenditure. Furthermore, overall acceptance of genetic technologies is likely to expand scientific knowledge. The more people are willing to participate in genetic studies, the greater the potential for further advances in understanding human genetics and the genetic basis of disease.

3. Genetic Information and the Health Insurance Industry

Access to genetic information is also particularly valuable to the health insurance industry. Insurance risk assessment is based on information. Generally, through a process called “medical underwriting,” health insurers assess and classify the degree of risk and make a decision whether, and on what basis, to accept an applicant for insurance. Identifying a person’s genetic status

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17 Id.

18 RISK FACTORS FOR BREAST CANCER, supra note 9.


20 Holmes, supra note 16, at 532. Insurance companies base underwriting decisions on a variety of tools. These tools include direct questions on the application form (e.g., “Have you or any of your family members ever been diagnosed with breast cancer?”), the applicant’s medical records, and medical examinations conducted for insurance purposes. See Sharona Hoffman, Unmanaged Care: Towards Moral Fairness in Health Care Coverage, 78 IND. L.J. 659, 666 (2003). In addition, underwriters also use information services such as the Medical Information Bureau (“MIB”), Id.; The MIB is a nonprofit trade organization of more than 700 insurance providers that has a database containing medical information on approximately 15 million Americans. See OFFICE OF TECHNOLOGY ASSESSMENT, PROTECTING PRIVACY IN COMPUTERIZED MEDICAL INFORMATION, 32-33 (1993). Generally, when people apply for insurance, they sign a waiver authorizing the insurance company to report any significant medical information on the insurance application to MIB and to obtain any records the MIB has. See SIMSON GARFINKEL, DATA BASE NATION: THE DEATH OF PRIVACY IN THE 21ST CENTURY, 136-137 (O'Reilly 2000).
and mortality risk allows health insurers to assess the likely future medical costs more accurately and establish premium rates that closely correlate with his or her estimated risk.

When applicants have more information about their risk of illness than insurers do, the insurers cannot accurately distinguish between high and low risk people. Asymmetric information forces the insurers to charge the same rates for applicants with different expected costs. The costs of high-risk people are passed along to all policyholders in some form – either through higher premium rates, fewer services, or lower quality services. This may not only be viewed as an unfair distribution to low-risk individuals, but also give rise to the problem of adverse selection.²¹

Suppose an insurance company is not able to identify individuals with greater risk, whose premium rates should be selectively increased. The insurance company compensates by charging premiums based on an average probability of loss. Low-risk people are forced to pay more than their expected costs to the insurer. The relatively high price drives out low-risk people while retaining high-risk people. As the remaining pool has a greater probability of loss, the insurance company is forced to raise the cost of premiums. If low-risk people continue to leave the insurance pool, insurance rates spiral even higher. The effects of adverse selection not only threaten the right of lower risk policy holders to have affordable health insurance, but also the financial stability of insurers.

The use of genetic information for medical underwriting purposes, though vital for the health insurance industry, may pose substantial barriers to the utilization of scientific advances generated from genetic research. More specifically, it may dilute incentives to seek out genetic diagnosis. Thus, fearing that unfavorable genetic diagnosis could detrimentally affect their health insurability, some might be dissuaded from utilizing genetic services in the first place. This outcome is undesirable, as it is likely to diminish the potential private and social value of genetic information. In other words, foregoing genetic services out of concern over possible repercussions on health coverage may not only be harmful for individuals, but also prevent society from reaping the full benefit of genetic research.

An argument invoking the potential destruction of incentives to utilize genetic advances was often employed by commentators who support legislation proscribing the use of genetic information by the health insurance industry.²²

²² See, for example, Larry Gostin, Genetic Discrimination: The Use of Genetically Based Diagnostic and Prognostic Tests by Employers and Insurers, 17 AM. J.L. & MED. 109, 113 (1991) (“If fear of discrimination deters people from genetic diagnosis and prognosis, renders them less willing to confide in physicians and genetic counselors, and makes them more concerned with the loss of a job or insurance than with care and treatment, the benefits of genetic data collection will
Indeed, as will be discussed at more length later, removing limitations on the utilization of genetic technologies was the principle motivation for genetics prohibitive legislation.23

C. Arguments For and Against the Use of Genetic Information by the Health Insurance Industry

While health insurers’ having access to most regular medical information is generally viewed as acceptable, access to genetic information has generated a considerable policy debate. Some academics believe that there is no reason to treat genetic information differently from regular medical information.24 Other academics believe that genetic information warrants special legal protection.25 Apart from the argument that the use of genetic information by the health insurance industry might reduce incentives to seek out genetic diagnosis, defenders of genetic-specific legislation put forward several additional justifications to support their position.

1. Effect of Genetic Information on Insurability

One argument often employed by opponents of health insurer’s use of genetic information was that health insurers’ access to genetic information would negatively affect the likelihood of obtaining health coverage.26 Access to genetic information allows health insurers to assess an individual’s risk of illness more accurately. Based on genetic information, health insurers may deny coverage, exclude coverage for certain medical conditions, or increase the premium rates. If this situation occurs, the genetically unfortunate – those who most need coverage – may not be able to get insurance or to afford the premium.27 According to this reasoning, distributing the risk over a large population is preferable, since it is likely to make health insurance more accessible and affordable to those who need it most.

Despite the great public fear that health insurers will use genetic information to make coverage determinations, surprisingly, there is very little evidence that health insurers are currently using genetic test results in the

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23 See supra note 2, at 738 (noting that “increasingly, commentators and legislators worry that public fears may prevent society from reaping the full benefits of genetics. One worry is that the fear will dissuade people from obtaining genetic testing that might be beneficial to their health or from participating in genetics research.”)

24 See, for example, Rich & Ziegler, supra note 1, at 22; See also Suter, supra note 2 (arguing that genetic information is not qualitatively unique and that legal protection should extend to other medical information).

25 The idea that genetic information is qualitatively different from other forms of medical information and therefore warrants special protection is commonly referred to as “genetic exceptionalism.” Thomas Murray was the first to use the term. See Thomas H. Murray, Genetic Exceptionalism and “Future Diaries”: Is Genetic Information Different from other Medical Information?, in GENETIC SECRETS: PROTECTING PRIVACY AND CONFIDENTIALITY IN THE GENETIC ERA 60, 61 (Mark A. Rothstein ed., 1997).

26 Holmes, supra note 16, at 558; Lovejoy supra note 1, at 891.

27 Holmes, id.
underwriting process. However, commentators believe that this may change. As one commentator notes, “[the fact] that health insurers are not using this information at present does not mean that, given the proliferation of genetic tests, they will not resort to using such information in the future.” As genetic testing becomes more common and the number of medical conditions that can be tested increases, and as the cost of genetic testing declines, there is a potential for increasing use of genetic information by the health insurance industry.

2. Genes are Beyond One’s Control

Another argument that some critics of health insurers’ access to genetic information proffer is that genes are beyond individuals’ control. In essence, this is a fairness-based justification that rests on the assumption that people should not bear the consequences of their immutable traits, even if those traits are statistically associated with loss. This line of reasoning rests on the assumption that risk classification based on genetic information is, like classification based on race or national origin, discriminatory rather than legitimate.

3. Misunderstanding Genetic Information

Another concern is that health insurers will misunderstand genetic information. Genes do not equal fate, and genetic diagnosis does not provide conclusive results. Some genetic disorders, Huntington’s disease for example, are almost certain to affect the people who carry that genetic defect. In most cases, however, there is no simple link between genes and disorders.

Onset of an illness may be a result of complex interactions between genetic and environmental factors. This means that most genetic diseases are

28 Jennifer S. Geetter, Coding for Change: The Power of the Human Genome to Transform the American Health Insurance System, 28 AM. J.L. & MED. 1, 50 (2002); See also Greely, supra note 2, at 1489 (indicating the “shortage of clear, well-documented examples of genetic discrimination in health insurance”. In addition, noting, “There have been a few studies that have purported to find such genetic discrimination. They generally have relied on unexamined reports from people who said they had been discriminated against and on the second-hand reports of genetic counselors who had been told that this had occurred.”). See also Deborah Hellman, What Makes Genetic Discrimination Exceptional?, 29 AM. J. L. & MED. 77, 86 (2003).

29 See, for example, Hellman, id.; See also Mary R. Anderlik And Mark A. Rothstein, Privacy and Confidentiality of Genetic Information: What Rules for the New Science?, ANNU. REV. GENOMICS HUM. GENET. 401, 423 (2001) (“The finding that there is no widespread genetic discrimination in health insurance at present does not necessarily undermine the case for regulation.”)

30 Geetter, supra note 28, at 51.

31 Ruth Chadwick & Charles Ngwena, The Human Genome Project, Predictive Testing and Insurance Contracts: Ethical and Legal Responses, 1 RES PUBLICA 115, 129 (1995) (“should testing technology in future be refined so as to produce a cheap and reliable test, there is no reason why insurers might not take up predictive testing as part of the normal underwriting process.”)

32 Rich & Ziegler, supra note 1, at 17 (referring to this argument and arguing that it cannot serve as a justification for legislation prohibiting the use of genetic information).

33 Holmes, supra note 16, at 557-567 (discussing how the use of genetic information by health insurers is subject to abuse and confusion).

34 OFFICE OF TECHNOLOGY ASSESSMENT, GENETIC MONITORING AND SCREENING IN THE WORKPLACE 92-93(1990), (indicating that genetic tests detecting the Huntington Disease gene are approximately 99% accurate).

35 For a discussion of the uncertain value of genetics as a predictive tool, see Paul M. Schwartz,
difficult to predict solely by means of genetic analysis. Genetic diagnosis may uncover susceptibility to a particular illness, but cannot predict the probability of developing the disease, the exact time the disease will manifest itself, or the severity of the symptoms. As insurers are not adequately aware of the limitations of genetic information, some commentators feared that they would base important decisions on this uncertain information, and treat individuals who are merely carriers of defective genes as if they had already manifested a disease.

4. Privacy

Privacy interests have also sparked particular attention. Privacy advocates argue that genetic information is particularly sensitive and personal, that it involves “an unusually broad spectrum of privacy concerns,” and may reveal “unique, involuntary, and presently immutable attributes of our genetic endowment.” This aspect is even more complicated by the fact that genetic information may reveal information not only about the individual, but also about family members, and “expose them – sometimes without their consent – to physical, psychological, and social harms.” Informed by the unique characteristics of genetic information, a number of scholars have advanced the argument that genetic information is potentially even more sensitive than ordinary medical information, and therefore “merits unique privacy protection.”

While supporters of protective legislation attempt to highlight the distinctive features of genetic information, opponents usually posit that the various arguments that have been put forward in support of special legal protection for genetic information actually fail to establish a weighty difference between genetic and regular health-related information.
those critics contend, is neither more revealing, private, nor sensitive to abuse or misunderstanding than other regular sources of medical information. More specifically, those critics hold that justifications like the potential effect of the information on insurability, the private nature of the information, and concerns that people will be penalized for risk factors beyond their control, apply with equal force to regular medical information.

However, most opponents of genetic-specific legislation do acknowledge that the only rationale that apparently explains why only genetic information merits special legal attention is one that emphasizes the individual’s incentive to utilize genetic technologies. Again, according to this argument, prohibition on health insurers’ use of genetic information is necessary in order to allay public fear and remove barriers that are likely to thwart the full realization of genetic science. This justification does not center on the idea that genetic information per se is unique. Rather, it rests on the assumption that without legal action privileging genetic information, people will be dissuaded from seeking genetic diagnoses. Yet, opponents of genetic-specific legislation often dismiss this rationale as well, on the grounds that it lacks an evidentiary basis.

D. Laws Prohibiting the Use of Genetic Information by the Health Insurance Industry

Notwithstanding the lack of academic consensus concerning the uniqueness of genetic information and the desirability of genetic-specific legislation, policymakers decided to resolve the debate in favor of special legal protection for genetic information.


On May 21, 2008, following thirteen years of continual legislative attempts, Congress passed the Genetic Information Nondiscrimination Act of 2008 (GINA). GINA bars health insurers and employers from making employment and coverage determinations based on genetic information.

It is clear that GINA’s promoters turned a blind eye to the various arguments supporting genetic legislation that could arguably apply to regular

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45 Rich & Ziegler, id.
46 Hellman, supra note 28, at 92-93; Suter, supra note 2, at 739 (“To many, this justification for genetics legislation [that public fear will dissuade people from seeking genetic diagnosis or participating in genetic research] carries special force because it appears to be the only one that seems truly unique to genetic information.”)
47 Hellman id. at 95 (“It is not enough to cite studies documenting the fact that people fear genetic discrimination. One must determine in what contexts people fear genetic discrimination as well as to what degree… This discussion suggests that more empirical research is needed about precisely what sorts of protective legislation would indeed allay people’s fears and, more importantly, affect their decisions about whether to be tested or to participate in research involving testing.”). See also Suter id. at 740-741 (“[I]t is unclear how much fears of genetics discrimination actually inhibit the public from participating in genetic testing or research… Clearly we need better data. At this point we have too little to dismiss it as a non-problem.”)
48 See, supra note 1 and accompanying text.
medical information. Instead, presumably to minimize controversy and blunt much of the criticism surrounding genetic-specific legislation, the findings section of GINA presents only the rationale that seems to apply uniquely to genetic information. Indeed, the only stated impetus for the adoption of GINA is to alleviate individuals’ concerns about the potential misuse of genetic information, for the purpose of promoting a broad public utilization of genetic advances in medicine. As the findings section of GINA specifically proclaims, “Federal legislation … is necessary to fully protect the public from discrimination and allay their concerns about the potential for discrimination, thereby allowing individuals to take advantage of genetic testing, technologies, research, and new therapies.”

In the pursuit of its stated objective, GINA establishes comprehensive protection against the use of genetic information. Title I of GINA, which regulates the use of genetic information the health insurance industry, bars health insurers in both the individual and group markets from considering genetic information in determining applicants’ eligibility or premiums. The comprehensive protection offered by GINA is apparent not only in its broad application to the various players in the health insurance industry, but also in its all-inclusive definition of “genetic information.”

GINA’s definition of “genetic information” encompasses a wide variety of genetic tests, as well as a broad range of family medical information. Protected “genetic tests” include, under GINA, “analysis of human DNA, RNA, chromosomes, proteins, or metabolites that detects genotypes, mutations, or chromosomal changes.” Genetic tests do not include, however, “an analysis of proteins or metabolites that is directly related to a manifested disease.” This means that while GINA proscribes the use of a broad range of laboratory techniques that can predict the onset of a future disease, it does allow health insurers to increase the cost of insurance for people who are already affected with a genetic disease.

GINA’s prohibition of the use of family medical history in making coverage decisions is also remarkably broad, and includes a wide spectrum of health information concerning family members. Under GINA, health insurers are barred from considering the results of genetic tests of the applicant’s family members, and any manifestation of a disease or disorder in family members of the applicant. GINA also prohibits use of information about any fetus carried by a pregnant woman, and about any embryo legally held by the individual or family member utilizing assisted reproductive technology. The term “family member” embraces, under GINA, up to fourth-degree relatives. As with the

49 GINA § 2(5).
50 Id. § 102(a)122 Stat. at 890-91.
51 Id. § 102(a)122 Stat. at 890.
52 Id. § 102(a)122 Stat. at 891.
53 Id. § 102(a), 102(b) 122 Stat. at 890, 895.
54 Id. § 102(a)122 Stat. at 890.
prohibition on the use of genetic tests, the ban on the use of family medical information to assess risk only applies when the individual is asymptomatic.\footnote{Id. §102(a), 102 (b) 122 Stat. at 888, 893.} Once a disease manifests itself, health insurers are allowed to increase the premium rate for the affected individual.

To further enhance the public willingness to utilize genetic services and remove prospective barriers to participation in genetic research, the term "genetic information" also covers, under GINA, "any request for, or recipient of, genetic services, or participation in clinical research which includes genetic services" by the applicant or family members of the applicant.\footnote{Id. § 102(a), 122 Stat. at 890.} "Genetic services" include genetic tests, genetic counseling (which includes obtaining, interpreting or assessing genetic information), and genetic education.\footnote{Id. § 102(a), 122 Stat. at 891.} GINA’s health insurance provisions will take effect in May 2009.\footnote{Id. § 102(b), 122 Stat. at 895-96.}

To be sure, GINA is not the only act regulating the use of genetic information in the realm of health insurance. Statutes prohibiting health insurers from denying coverage or basing premium rates on genetic information had been enacted at both state and federal levels even prior to GINA’s passage. Those laws, however, were incomplete, both in their scope and their depth of protection. In particular, there was no consensus on the scope of the protection offered by genetic legislation. Most importantly for the purpose of this essay, information about family medical history was not entirely protected. The remainder of this section reviews the legislative landscape at the pre-GINA stage.

2. The Health Insurance Portability and Accountability Act

The Health Insurance Portability and Accountability Act (HIPAA,)\footnote{Pub. L. No. 104-191, 110 Stat. 1936 (codified in scattered sections of 26, 29, and 42 U.S.C.).} enacted in 1996, includes the first federal protection against genetic discrimination. HIPAA prohibits group health plans from using genetic information as a basis for denying or limiting eligibility for coverage or for charging higher premium rates. The term “genetic information,” as defined in the regulations promulgated under HIPAA, covers various genetic information sources, including family health information. In the words of the HIPAA regulations, “genetic information means information about genes, gene products, and inherited characteristics that may derive from the individual or a family member. This includes information regarding carrier status and information derived from laboratory tests that identify mutations in specific genes or chromosomes, physical medical examinations, family histories, and direct analysis of genes or chromosomes.”\footnote{See 45 C.F.R. 144.103 (2005).}

In contrast to GINA, HIPAA does not establish a national and uniform standard. Specifically, health insurers offering coverage in the individual market

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\textsuperscript{55} Id. §102(a), 102 (b) 122 Stat. at 888, 893.
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\textsuperscript{56} Id. § 102(a), 122 Stat. at 890.
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\textsuperscript{57} Id. § 102(a), 122 Stat. at 891.
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\textsuperscript{58} Id. § 102(b), 122 Stat. at 895-96.
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\textsuperscript{60} See 45 C.F.R. 144.103 (2005).
are not within the ambit of HIPAA. HIPAA only applies to employer-based and commercially issued group health insurance. According to the US Census Bureau, in 2005, 59.5% of covered individuals had employment-based health insurance. As a result of HIPAA’s limited purview, regulation of genetic information of people seeking health insurance in the individual market — who account for 10-15% of all insureds — has been left up to the individual states.

3. State Genetic Nondiscrimination Laws

By the time GINA was enacted, forty-seven states had statutes banning the use of genetic information by health insurers for underwriting purposes. State laws however, varied quite dramatically with respect to their level of protection. Some states, like New Jersey, define genetic information broadly. A broad definition of genetic information includes, for example, information about the individual’s genetic make-up or genotype, whether derived directly from genetic testing methods or indirectly from other sources. Other states, Florida and Arkansas, for example, define genetic information narrowly, as including only information derived from genetic testing. Both states explicitly exclude information derived from family health history from the definition of genetic information.

Before GINA’s passage, the patchwork of state and federal laws, and the varied definitions of the term “genetic information,” resulted in an environment in which several sources of genetic information were left unprotected. Most

61 US Census Bureau, Health Insurance Coverage, Figure 6, available at http://www.census.gov/prod/2006pubs/p60-231.pdf (last revised April 5, 2007).
62 Lovejoy, supra note 2, at 894.
63 Mark A. Rothstein, Putting the Genetic Information Nondiscrimination Act in context, 10 GENETICS IN MEDICINE, 655, 655(2008).
64 N.J. Stat. § 17B:30-12 (e)(2).
65 New Jersey defines “genetic information” as “information about genes, gene products or inherited characteristics that may derive from an individual or family member.” “Genetic test” is defined as “a test for determining the presence or absence of an inherited genetic characteristic in an individual, including tests of nucleic acids such as DNA, RNA and mitochondrial DNA, chromosomes, or proteins, in order to identify a predisposing genetic characteristic.” Id.
68 Florida defines “genetic information” as “information derived from genetic testing to determine the presence or absence of variations or mutations, including carrier status, in an individual’s genetic material or genes that are scientifically or medically believed to cause a disease, disorder, or syndrome, or are associated with a statistically increased risk of developing a disease, disorder, or syndrome, which is asymptomatic at the time of testing. Such testing does not include routine physical examinations or chemical, blood, or urine analysis, unless conducted purposefully to obtain genetic information, or questions regarding family history.”; Arkansas defines “genetic information” as “information derived from the results of a genetic test” and explicitly excludes family history. “Genetic test” is defined as “a laboratory test of the DNA, RNA, chromosomes, or enzyme activity for genetic disease of an individual for the purpose of identifying the presence or absence of inherited alterations in the DNA, RNA, chromosomes, or enzyme activity for genetic disease that cause a predisposition for a clinically recognized disease or disorder.” The definition of “genetic testing” varies among the states, but since this essay focuses on genetic information derived from family health history, detailing the varied definitions of genetic testing is beyond its scope.
69 Id. and accompanying text.
important for the purpose of this essay, family medical information was not always covered. In some states, health insurers offering coverage in the individual market could freely use family health information, such as a parent’s death from Huntington’s disease (an inheritable characteristic), instead of a genetic test, to assess an applicant’s risk. The comprehensive protection established by GINA has finally closed the family medical history gap.

E. Actual Use of Family Medical Information by the Health Insurance Industry

Prior to the national protection established by GINA, health insurers’ use of family medical history probably did not occur on a large scale. According to an empirical study conducted by Mark A. Hall, Professor of Law and Public Health at Wake Forest University, and Stephen S. Rich, Professor of Public Health Sciences at University of Virginia, even in states that did not prohibit the use of family health information in medical underwriting, family medical history was not often used by health insurers to predict future onset of disease that had not yet manifested. Instead, this study found that in the majority of the cases examined in the survey, family medical history was used by health insurers to evaluate current or previous health problems. For example, a family history of heart problems served as a red flag in evaluating the risk level of someone with existing high blood pressure or high cholesterol levels.

Yet, there is some evidence that health insurers used family medical history to evaluate risk even in the absence of symptoms indicating existing illness. Mark & Rich themselves identified four cases in which health insurers used only family medical information to make coverage determinations. In addition, Prof. Lori B. Andrews pointed to cases in which “relatives of people with Huntington’s disease have been refused health insurance,” and to another case in which “a health insurance company told a woman whose mother had breast cancer that she could obtain health care coverage, but not for any treatment of breast cancer.” Whatever the precise extent of the use of family medical information in the medical underwriting process, there is enough data to conclusively support the existence of this practice.

72 Id. at 298-299.
73 Id. at 299.
74 Id. at 296.
76 Id. at 259.
III. IS FAMILY MEDICAL HISTORY DIFFERENT? AN ECONOMIC ANALYSIS

As explained in the previous Part, the driving force behind the enactment of GINA was to allay public fears and encourage individuals to utilize the medical benefits derived from genetic research. At heart, GINA’s justification is merely another version of the argument that society should promote efficiency by encouraging the search for socially useful information.

Different branches of the law seek to promote efficiency by providing special legal protection to socially beneficial information. Intellectual property laws are an obvious example. A similar rationale seems to underlie GINA. The line of reasoning is as follows. Genetic information is socially useful in nature. Advances in human genetics hold great potential for improved medical care and public health. Assuring individuals that information about their genetic profile will be kept confidential, so the argument goes, will increase incentives to seek out genetic information. This will, in turn, the argument continues, allow society to reap the full potential of the scientific knowledge gained from biomedical and genetic research.

Despite GINA’s straightforward intention – encouraging the search for genetic information – one large question still looms: is it necessary for the law to protect against health insurers’ access to both genetic testing and family medical history, or would safeguarding only genetic testing suffice? This Part attempts to answer this question.

The first step in answering the question is understanding how the law provides a supportive framework for acquiring information. Section A therefore explains some principles of the economics of information, which provides the theoretical foundation for examining the conditions under which government intervention is warranted in the effort to spur individuals’ collection of information. Section B then applies the economic principles in our setting. It shows that economic rationales seem to call into question the desirability of prohibiting the use of family medical history in medical underwriting. Section C expands the analysis to explain why protecting the confidentiality of family health information is nevertheless a wise policy choice.

A. Principles of the Economics of Information

Economics of information theories conclude that an unregulated market tends to undersupply public goods such as information.\(^77\) To remedy this market failure, efficiency principles seek to encourage the search for socially valuable information.\(^78\) One effective way of encouraging such searching is to assign

\(^77\) ROBERT COOTER & THOMAS ULEN, LAW AND ECONOMICS 121 (4th ed., 2004) (“An unregulated market will undersupply creative works that embody ideas, such as science, inventions, books and paintings.”)

\(^78\) Id. at 282 (“The state must take special measures to reward people who discover productive information.”)
property rights to the information. A right to exclude others increases incentives to acquire valuable information, since it enables individuals to enjoy the fruits of their search. To illustrate, intellectual property laws create incentives for inventive activities, as they reward the creator of an idea by granting him exclusive property rights that allow appropriation of the idea’s value. In contrast, an obligation to disclose the information is antithetical to the idea of property rights because it prevents individuals from exploiting the private benefits of the information. Denying property rights to information dilutes incentives to acquire it, resulting in less socially beneficial information.

The social desirability, or lack thereof, of legal measures that encourage the search for information depends on a number of factors; two of them are particularly applicable to this essay. The first factor is whether the information is socially beneficial or has only private value. The state has a special interest in increasing the amount of socially productive information, that is, information that can produce more wealth, or otherwise enhance public welfare. For this reason, legal actions motivating a search for information are usually taken when the information is socially valuable.

In contrast to information that is socially beneficial, information that has only private value generally does not require special actions to induce its collection. The reason is straightforward: when information can generate private benefit, individuals are likely to become informed, whether or not laws encourage the gathering of the information. Spending resources to encourage the search for privately beneficial information would therefore be a waste.

Complex cases may arise however, when the information is of both social and private value. In fact, even when the information can yield private benefit to individuals who acquire it, supportive legislation is nevertheless sometimes socially desirable. This holds true, for instance, when, despite the private value

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79 See Anthony T. Kronman, Mistake, Disclosure, Information, and the Law of Contracts, 7 J. LEGAL STUD. 1, 14 (1978) (arguing that “One effective way of insuring that an individual will benefit from the possession of information… is to assign him a property right in the information itself – a right or entitlement to invoke the cohesive machinery of the state in order to exclude others from its use and enjoyment.”)
80 COOTER & ULEN, supra note 77, at 122; See also Kronman, id. at 14 (“The legal protection accorded patented inventions and certain trade secrets are two obvious examples.”)
81 Kronman, id. at 15.
82 Id. at 16.
83 STEVEN SHAVELL, FOUNDATIONS OF ECONOMIC ANALYSIS OF LAW, 332-34 (2004) (discussing the factors that are being considered in assessing the social desirability of disclosure obligation in contract law). Note that an efficiency based analysis examining the social desirability, or lack thereof, of a legal obligation to disclose information was most often applied in economic analysis of contract law. See, for example, Kronman, id. See also COOTER & ULEN, supra note 77, at 280-283. Nevertheless, the same theoretical framework seems particularly useful in our context. See Kronman id. at 33-34 (arguing that “the theoretical approach may prove to be useful in analyzing related problems in other areas of the law.”)
84 SHAVELL, id. at 334.
85 COOTER & ULEN, supra note 77, at 281.
of the information, other factors reduce the incentive to gather it in the absence of legal intervention.\textsuperscript{86}

The second factor is whether the acquisition of the information is the result of an active search.\textsuperscript{87} The method by which information is acquired is extremely important for efficiency analysis. There are two possible methods by which individuals can obtain information. One can either acquire information deliberately, meaning by an active investment of time and resources, or casually – meaning, by chance.\textsuperscript{88} As Cooter and Ulen note, “there is a strong social interest in encouraging the investment of resources in acquiring valuable information… [Acquiring information] fortuitously is different, [since] there is nothing that society gains from more or less chance occurrence.”\textsuperscript{89} In other words, efficiency principles advocate rewarding only people who acquire socially valuable information as a result of an active search.\textsuperscript{90} There is no similar efficiency case to be made in favor of people who discover productive information without making a deliberate investment in seeking it out. This is because denying individuals property rights to casually acquired information (or subjecting them to an obligation to disclose the information) is unlikely to affect the production of socially useful information.\textsuperscript{91}

B. Genetic Testing versus Family Medical History: Does the Difference Make a Difference?

We can use the theoretical framework about the nature of information and the method by which information was acquired in order to analyze the difference, or lack thereof, between information derived from genetic testing and information derived from family health history. Consider the first factor: the social versus private nature of the information. As discussed earlier, genetic test results have limited stand-alone value.\textsuperscript{92} Family health information is used to interpret the results of genetic testing and make more accurate predictions about the individual’s risk of developing a particular genetic disease.\textsuperscript{93} The link between family medical information and genetic testing renders both sources equally important in achieving public health benefits. The health promoting potential of both sources qualifies them as socially beneficial in nature. Since genetic information derived from both genetic testing and family health information has

\textsuperscript{86} \textit{SHAVELL}, supra note 83, at 333 (indicating that one of the factors determining the social desirability, or lack thereof, of disclosure obligation in contract law is whether incentives to acquire information would be undesirably diluted by the obligation to disclose).

\textsuperscript{87} \textit{See} COOTER & ULEN, supra note 77, at 281-283; Kronman, \textit{supra} note 79 (both sources apply this factor in the context of economic analysis of contract law).

\textsuperscript{88} COOTER & ULEN, \textit{id.} at 282; Kronman, \textit{id.} at 13.

\textsuperscript{89} COOTER & ULEN, \textit{id.} [Emphasis added].

\textsuperscript{90} \textit{Id.} at 282-283.

\textsuperscript{91} Kronman, \textit{supra} note 79, at 15-16.

\textsuperscript{92} \textit{See} discussion, \textit{supra} in Part II.A.

\textsuperscript{93} \textit{See} \textit{id.} and accompanying text.
social value, a strong case can be made for legislation encouraging the acquisition of both sources.

One might argue, however, that both genetic test results and family medical information have private value too. Individuals already have (or at least should have) a strong incentive to possess information concerning their own health, whether or not the law protects medical information. Yet, as the findings section of GINA implicitly suggests, underlying the enactment of GINA is the assumption that an obligation to disclose genetic information to health insurers would reduce the incentive to seek it out. Under this premise, protective legislation that will encourage its acquisition is desirable, even though genetic information has definite private value.

The method by which the information is acquired, i.e., whether actively or fortuitously, remains the only criterion that matters. In fact, if we apply this factor in our context, we can justify differentiating between genetic testing and family medical history. To appreciate how, let us first consider genetic testing.

Information about genetic test results is not naturally in the possession of individuals. Rather, possessing the results of genetic testing is typically the fruit of a deliberate action. For that reason, economic rationales may suggest, there are strong efficiency grounds for encouraging the search for genetic testing by granting it special legal protection. Laws that impose an obligation to disclose genetic information gleaned from testing, or otherwise allow insurance companies to make adverse coverage determinations based on those results, discourage the socially-beneficial quest for genetic testing. Such laws should therefore be suppressed for the sake of efficiency.

Family medical history, however, is considered to be different. Most often, this type of information is not the product of a deliberate search. People are unable to turn a blind eye to diseases that run in their family. Once a family member develops a disease that has genetic roots, relatives can easily recognize that they may also be at risk. The visible nature of family medical information makes it essentially comparable to information that was obtained by chance, thereby rendering its legal protection worthless. After all, denying legal protection to the family medical information is unlikely to reduce its social amount.

To be sure, familial diseases are not always readily observable, nor information about them freely shared among family members. At times, obtaining the information may require some active search. For instance, one may need to talk to relatives in order to ascertain current or historical family medical conditions. Yet, since family health information can usually come into the possession of individuals easily, the effort its search requires is viewed as relatively low. As family medical history is generally accessible, so the argument goes, there is no efficiency case for privileging this information.

The economic distinction between deliberately and casually acquired information can also be used to explain why genetics legislation should afford
equal protection to everyone who undergoes genetic testing. From a standpoint that places emphasis on the method by which the information is acquired, those with problematic family histories who decide to undergo genetic testing are quite similar to those with “clean” family histories who go through the testing. It is therefore understandable that the same legal protection should be applied to both groups. In other words, consistent with the economic perspective, individuals with genetic diseases affecting their families who seek out genetic testing are also awarded protection for their active investment: that is, should their test results reveal that they carry the suspected familial gene, they will be reassured that the results will have no affect on their insurance coverage.

At first blush, efficiency rationales appear to cast doubts on the desirability of barring the use of family medical history in medical underwriting. Rather, economic reasoning seems to propose that only genetic information derived from genetic test results should be subject to prohibitive legislation. However, does the economic reasoning truly provide a solid foundation for the exclusion of family medical history from legal protection? The next section examines more closely empirical and scientific data surrounding family medical information and reveals that the true picture is much more complex. As the next section shall clarify, contrary to initial impressions, the acquisition of family health information does require a deliberate search.

C. Tracing the Family Medical History: The True Picture

As explained earlier, the tremendous potential value of genetic testing as a predictive tool is limited without the integration of family medical history.\textsuperscript{94} Family health information helps health professionals to interpret genetic test results and predict the risk of developing a hereditary disease more accurately.

To make the genetic diagnosis optimal, a detailed family medical history is required. Medical scientists maintain that for family history information to be most effective in the genetic diagnosis process, it should include information on at least \textit{three generations}.\textsuperscript{95} To be most useful, a three-generation history should include information about current age, medical problems, the age of onset of the medical conditions, and the age and cause of death for deceased family members.\textsuperscript{96} The more complete the family tree, the more reliable the resulting information becomes.

To be sure, a complete and accurate family medical history, let alone three generations of information, is not often forthcoming. In fact, obtaining thorough family health information may well require an active investment of time and resources. The exertion involved in collecting family medical information depends to a large extent on the size of the family, the accessibility of the family

\textsuperscript{94} See \textit{id.} and accompanying text.
\textsuperscript{95} Alvarado et al., \textit{supra} note 11, at 35; Rich et al., \textit{supra} note 11, at 274.
members, and their willingness to share sensitive medical information. Tracing the family tree may require conducting interviews with relatives, and even obtaining death certificates, which usually provide information about both the date and the cause of death.\(^97\)

Gathering a detailed family medical history, however, is unlikely to suffice. After collecting family health information, patients are usually encouraged by physicians and genetic specialists to organize the information into a graphic family tree (“pedigree”).\(^98\) A visual depiction of the information helps illustrate how traits are moving through the family, thereby facilitating analysis of the data.\(^99\) Currently, instructions for drawing a pedigree and a variety of computer-based tools that record family medical history are widely available on the Internet.\(^100\)

Gathering extensive family health data, organizing the information into a pictorial representation, and keeping it up to date, is unquestionably an ambitious undertaking. To be sure, grappling with family medical history is considerably more intricate and time-consuming than just drawing a blood sample.

The detailed family health information that is required, along with the scale of endeavor involved in its acquisition, seem to shed a new light on the controversy over the socially desirable breadth of protection offered by genetics legislation. The considerable effort accompanying the collection of accurate and extensive family health information shows that the exclusion of family medical history from the bounds of genetics legislation lacks compelling justification. The point here is simply that if efficiency demands encouraging the search for productive information that is acquired through “active investment,” then there are no plausible grounds for affording special legal protection to those who obtain genetic test results, but to deny such protection to those who research their family medical tree.

D. Encouraging the Search for Family Health History

A legal obligation to disclose family health information to health insurers may have far-reaching implications that are undesirable for individuals, families, and society at large. As genetic science explains more diseases, gathering family


\(^99\) Id.; See also Rich et al., supra note 11, at 278 (indicating that most of the authors of this article find that organizing family medical history graphically is most helpful).

medical information is likely to become increasingly common. In the absence of legal protection for family health information, there may be substantial barriers to its thorough collection. Fearing adverse impacts on health insurability of either self or family members, people will avoid tracing comprehensive family medical information. Given the key role of family medical history in medical genetics, barriers to attaining family health information may ultimately frustrate the chief objective underlying genetics legislation – reaping the full benefit of scientific knowledge gained from genetic research.

A recent survey conducted by the US Center for Disease Control and Prevention provides telling evidence of the current low quantity of socially valuable family health information. According to the survey, 96% of Americans believe that knowing their family history can be beneficial, yet only 33% have ever attempted to gather and organize their family health history. These alarming findings clearly reinforce a growing need to strengthen families’ incentives to learn about their health histories.

To enhance public awareness about the importance of family health history and encourage Americans to gather that information, in 2004 the US Surgeon General, in collaboration with a number of agencies in the US Department of Health and Human Services, launched a national public health campaign called the US Surgeon General’s Family History Initiative. The campaign establishes Thanksgiving, when American families traditionally gather, as annual National Family History Day. To spur the collection of family health information, the Surgeon General’s initiative also included development of a free web-based tool that helps users organize their family health history into a detailed family tree, and save the information on their own computer.

The Surgeon General’s campaign, though presumably beneficial to some extent, is not enough. To be most effective, social efforts to inspire the gathering of family medical information should be backed by legislation. Reassuring individuals that their family medical history will have no negative implications for their health insurability is a necessary preliminary step towards encouraging people to learn about the health of their families. The conclusion, therefore, is that legislation that protects against health insurers’ access to both genetic testing and family medical history is preferable to legislation that only privileges the results of genetic testing.

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102 The National Human Genome Research Institute (NHGRI) at the National Institutes of Health, the Centers for Disease Control and Prevention (CDC), the Agency for Healthcare Research and Quality (AHRQ) and the Health Resources and Services Administration (HRSA).
104 This web-based tool is available at https://familyhistory.hhs.gov/.
VI. THE DEMISE OF THE GENETIC TEST RESULTS/FAMILY HISTORY DISTINCTION

The previous Part explained that in order to attain genetics legislation’s principle goal – encouraging the search for genetic information – it is insufficient to proscribe the use of genetic testing in medical underwriting. Rather, after identifying the substantial effort involved in the gathering of family health information, the previous Part showed that it is also necessary to prohibit health insurers’ use of family health history.

The discussion in this Part expands the analysis, and considers another important nexus between genetic testing and family health information. It shows that preventing the use of family medical information in medical underwriting is desirable regardless of the effort accompanying the acquisition of family health history and the social need to motivate individuals to search for it. In fact, as the discussion in this Part clarifies, protecting against health insurers’ access to family health information is a key ingredient in the effort to protect the confidentiality of genetic test results. Section A explains why it is virtually impossible to limit health insurers’ access to genetic test results without the simultaneous protection of family medical information. Section B then considers the policy implications of Section A’s findings.

A. Can the Distinction Between Genetic Test Results and Family Medical History be Sustained?

Genetic testing is a more reliable source of information for assessing one’s risk for hereditary conditions than information generated from family health history. The reason is twofold. First, family medical history is not exclusively genetic. The onset of the illness in the family may be related to non-genetic factors, such as “area of residence, quality of living conditions, diet, exposure to infectious diseases, stress,” as well as other environmental and behavioral patterns. For example, if someone’s grandfather and father both died of heart attacks during their fifties, that might have a genetic cause, but it also might be because they smoked, did not exercise, or refused to go for periodic checkups. Second, even if the illness in the family has genetic roots, not all family members may actually inherit the “defective” gene. Information derived from genetic testing can potentially determine an individual’s risk for developing the medical conditions affecting his or her family with greater certainty.

The relationship between family health information and genetic test results can have a significant impact on individuals’ behavior. Specifically, the verifiable nature of the risk associated with family medical history can affect the ability of individuals with signs of hereditary diseases in their family to negotiate (or renegotiate) the terms of their coverage. Thus, to lower the price of insurance, people who can demonstrate they are not at-risk for the genetic illness or medical

106 Id.
condition affecting their family may want to distinguish themselves from truly high-risk individuals through voluntary disclosure of favorable genetic test results.

Documented cases of policyholders with genetic conditions that run in their family who volunteered favorable genetic test results simply to dispel health insurers’ suspicious of their high-risk potential have so far been few. Yet, in a regime that allows the use of family health information in medical underwriting, this trend – people voluntarily disclosing their favorable genetic test results – is likely to continue and develop. Indeed, as genetic testing becomes more common and cheaper, there is a clear likelihood that more and more people who are presumed to be at high-risk due to their family history will selectively disclose to health insurers the results of their genetic tests in order to escape the high-risk pool, thereby qualifying for coverage, or more affordable coverage.

Statutes that practically pave the way for ameliorating the terms of coverage via disclosure of favorable genetic test results already exist. The Unfair Trade Practices Act (UTPA), which was developed by the National Association of Insurance Commissioners, and was adopted by all fifty states in some form or another, bans health insurers from “unfair discrimination between individuals of the same class and of essentially the same hazard.” Therefore, statutes based on the UTPA “may allow and even require” insurers to reduce the price of insurance for individuals whose premium rates were set at a higher level due to their family medical history, if their genetic test results can confirm they do not carry the problematic familial gene.

As soon as some people whose family medical information has unjustifiably affected their health coverage begin to voluntarily disclose information about their favorable genetic test results, it will eventually become impossible to prevent health insurers’ knowledge of sensitive results of genetic testing. In fact, the voluntary disclosure of information – usually described by game-theorists as “unraveling” – is likely to make information about unfavorable genetic test results transparent.

To appreciate how, consider the following example. Suppose there are ten applicants with problematic family health histories in the pool. Five of them are predisposed to the genetic conditions affecting their family (‘high-risk individuals’) and five are not predisposed (‘low-risk individuals’). The expected medical cost of low-risk individuals is 10 and that of high-risk individuals is 20.

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107 See, for example, Hall & Rich, supra note 71, at 296 (pointing to two cases in which insureds volunteered their genetic test results in order to dispel health insurers’ suspicion of high-risk potential based on their family medical histories).
108 See Hoffman, supra note 20, at 671.
111 Id. at 193-194.
112 For an introduction to the concept of unraveling, see BAIRD ET AL., supra note 21, at 89-109.
Results of genetic testing can potentially substantiate the level of risk of each individual. In the absence of access to genetic test results, the health insurer is not able to know each applicant’s level of risk. As a result, the insurers simply set the premiums of all ten individuals in the pool at 15, which is the average medical cost per applicant.

Now consider how a rule that allows the use of family health history in medical underwriting would affect the behavior of applicants with questionable family medical histories. Applicants already in possession of genetic testing indicating that they do not carry the “bad genes” affecting their family have an incentive to volunteer the results to insurers in order to remove doubts regarding their high-risk potential. After all, why be subject to coverage terms that have nothing to do with their actual genetic risk?

The rest of the applicants with problematic family medical histories will not reveal their genetic test results, either because their genetic testing corroborates that they have “defective genes,” or because they have never taken such tests. As the insurer is not able to tell whether applicants who remain silent are concealing information about their “bad genes,” or are simply unaware of their level of genetic risk, a rational insurer would respond by increasing the premiums for those who ‘fail’ to volunteer their genetic test results. More specifically, the insurer would adjust its pricing to be more commensurate with the individual’s expected risk: the cost of insurance for applicants with questionable family health histories who can provide genetic testing indicating their low-risk status would be, in our example, 10 and for applicants who cannot provide a “certificate of their good genes,” 20.

Consider now how the increased cost of coverage intensifies the pressure on individuals with questionable family medical histories who have never taken a genetic test to submit to the testing. Assume that the cost of genetic testing is 2 and the probability of having favorable results is 0.5. The marginal benefit of undergoing genetic testing – that is, the amount applicants expect to save by going through testing – is therefore \((20-10) \times 0.5 - 2 = 3\). Given the positive benefit of genetic testing, each applicant’s best response is to undergo testing.

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113 Deborah Wilson, *Acquisition and Disclosure of Genetic Information Under Alternative Policy Regimes: An Economic Analysis*, 1 HEALTH ECON., POL. & L. 263 (2006) (“Selective disclosure of only favorable genetic test results will lead insurers to believe that unfavorable results are being withheld.” *Id.* at 269. Wilson argues that “given that the insurer knows the enrollee has access to genetic testing, a report of ignorance leads the insurer to believe that the risk level is the highest possible, even if it is not.” *Id.* at 270). See also Gulati, supra note 110, at 194 (“If individuals are allowed to use affirmative medical defenses, the consequence will be that those who do not use these defenses will pay higher rates.”)

114 Gulati, *id.* (argues that once insurers charge higher rates from those who do not volunteer favorable genetic test results, “more and more people will be induced to forgo their desire not to get tested and to undergo genetic screening in the hope that they will have a clean bill of genetic health and thereby qualify for a lower premium.”)

115 \((20-10)\) which is the difference between the price of insurance for applicants who provide testing and those who do not provide*0.5 (the probability of having favorable results)*-2 (the cost of genetic testing).

116 This presumes that individuals who know they are not predisposed to the genetic conditions
The positive benefits of genetic testing will eventually provide incentive to all applicants with a record of a medical condition or illness affecting their family to go through the testing. In the end, those with favorable test results will voluntarily disclose the information to their health insurer, whereas the others – i.e., those with unfavorable genetic test results – will remain silent. Under these circumstances, silence conveys information. A rational insurer will therefore infer that applicants who withhold genetic test results have learned about their bad genes. It becomes evident how even without direct access to genetic test results, the insurer can make an educated guess about the genetic quality of those who remain silent. This upshot is what is known as the unraveling result: the incentive to signal high-quality which ultimately causes the recipient of information to appreciate that silence corresponds to bad news.117

The unraveling result calls into question the effectiveness of the genetics legislative scheme preceding GINA – when family medical information was largely left unprotected. As the analysis in this section shows, legislative attempts to privilege only the results of genetic testing cannot be sustained. Due to unraveling, the use of family medical history in risk classification results in the exposure of sensitive results of genetic testing. Ironically, health insurers’ knowledge of unfavorable genetic test results is precisely what genetics legislation preeminently sought to prevent.

B. Unraveling the Unraveling Problem

The logic of the unraveling problem – that one would voluntarily disclose information if allowed to do so, in order to prevent adverse inferences from being drawn from silence – provides guidance about how to formulate a sound and meaningful genetic policy. Indeed, to circumvent the unraveling problem, it is necessary to establish a mechanism that impedes the voluntary disclosure of genetic test results. In a world where no one bothers to disclose, insurers are not able to draw inferences from silence, and unraveling will not occur.

Note, however, that in order to avoid the unraveling phenomenon, lawmakers do not necessarily need to set limits on health insurers’ access to family medical history. Instead, it is enough to ensure that disclosure of genetic test results will not take place. In other words, as long as individuals do not disclose favorable genetic test results to insurers, unraveling will not occur – whether or not family medical history is being used to assess risk.

One possible way to prevent unraveling is therefore to allow the use of family medical history in risk classification, but at the same time frustrate voluntary disclosure of favorable genetic test results. Thwarting individuals’ attempts to disclose their favorable genetic test results can be done, for example, by prohibiting health insurers from adjusting the price of insurance on the basis affecting their family, i.e., that their expected medical costs are 10, are risk averse and therefore will not leave the pool even if the cost of insurance is raised to 20. 117 See BAIRD ET AL., supra note 21 and accompanying text.
of genetic test results, *irrespective* of whether those results can dispel misconceptions about genetic risks. This course of action, of course – though could truly solve the unraveling problem – is sounder in theory than in practice. The reason is simple and threefold. First, a rule that allows the use of family medical history in risk classification but prevents applicants who were unjustifiably classified as “high-risk” from demonstrating their good health, establishes medical underwriting that rests on ill-founded risk factors. It therefore satisfies neither the objective of accuracy, nor the principle of efficiency. Second, a law that seeks to prevent policyholders from refuting groundless assumptions about their high-risk potential fails to deal with the root of the problem: it does not remove incentives for individuals unjustifiably presumed to be at high-risk potential from signaling their low-risk status. Finally, a legal regime that prevents disclosure of genetic testing, but does allow insurers to consider family health history in determining premiums, results in inequality between similarly situated people. Specifically, if people with indications that inheritable conditions affect their family are required to pay higher rates but not allowed to remove doubts regarding their genetic profile, the upshot is that healthy people with problematic family medical histories are treated differently from healthy people with no family medical history. Clearly, a legal rule that purports to restrain the ability of individuals to dispel baseless risk determinations would be both hard to justify and hard to enforce.

The best practical solution is therefore comprehensive protection against health insurers’ use of genetic information, *i.e.*, a uniform federal genetics legislation that does not merely limit health insurers’ access to genetic testing, but also protects the confidentiality of family medical history. Banning the use of family health history in medical underwriting can effectively circumvent the implications of unraveling because it will dilute incentives to volunteer favorable genetic results of genetic testing.

A comprehensive legislation proscribing the use of diverse sources of genetic information in medical underwriting is precisely the solution advanced by GINA. As discussed earlier, GINA bars health insurers in both the individual and group markets from adjusting premium rates based on genetic information.118 Again, an individual’s “genetic information” is defined broadly under GINA to encompass both various genetic tests and a broad range of family medical information.119 GINA’s extensive scope of protection is a viable policy option that can effectively resolve the problem of unraveling. Indeed, if nothing else, the all-embracing legal protection established by GINA is superior to the statutory protection that prevailed at the pre-GINA stage.

118 See discussion, *supra* in Part II.D.1.
119 *Id.* and accompanying text.
V. Conclusion

The recent passage of GINA has put an end to a legislative landscape in which family medical history – an obvious source of genetic information – was not entirely protected. This essay offered an economics-based justification for GINA’s comprehensive scope of protection.

By drawing attention to the fundamental shortcomings of a narrow legal protection of genetic information, the analysis in this essay has sought to demonstrate two points. The first is that there is no clearly perceived and well-reasoned basis for privileging information derived from genetic test results, while leaving family medical information unprotected. Highlighting the central role of family health information in medical genetics, and the substantial effort accompanying its acquisition, this essay showed that protecting against health insurers’ use of family health history is a wise policy decision.

The second point is that maintaining a stable distinction between genetic test results and family medical history is virtually impossible. Prior to GINA’s passage, lawmakers who privileged only the results of genetic tests assumed a great deal and ignored even more. They assumed that traditional family medical information is different from innovative genetic testing, but largely ignored the fragile nature of the dichotomy between disparate types of genetic information. Indeed, by trying to limit health insurers’ access to genetic test results alone, we were left with a false sense of having achieved a meaningful goal.

This essay did not purport to join the extensive debate on whether genetic information is unique, and thereby merits special legal attention. The recent enactment of GINA seems to call off this debate. This discussion also did not wish to prescribe the ultimate definition of “genetic information.” Rather, this essay sought to show that in a world where genetics matters, a broad definition of “genetic information” – one that includes both information derived from family members and genetic testing – is the only defensible option.