As part of their experiential learning, students in Insurance Law at the University of Iowa College of Law completed group white papers addressing a policy question at the intersection of genetics and insurance. These projects were developed as part of a grant from the National Human Genome Research Institute (NHGRI) examining life, long-term care, and disability insurer use of genetic information. For the projects, student groups often paired with genetic counselors from across the country to assist with questions about genetic testing and the implications of laws on the genetics community.

Prompt: Life, long-term care, and disability insurers are generally allowed to use genetic test results when underwriting, but state laws place some limits on this use. Which states have adopted these ‘unfair discrimination’ laws and how have they been enforced/litigated in practice? How should they be enforced/litigated in practice?

Disclaimers:
- This white paper is not meant to provide legal advice nor be a comprehensive assessment of the state laws regulating insurer use of genetic information. The white paper is intended to provide policy research and to illustrate students’ recommendations developed as part of a semester-long class project. Therefore, the white paper does not replace detailed fact and situation specific research.
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Use of Genetic Information in Life, Disability, and Long-Term Care Insurance

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EXECUTIVE SUMMARY

Since the successful completion of the Human Genome Project, genetic testing technologies have grown and become more accessible to consumers. As utilization of genetic testing increases, questions arise about allowable use of an individual’s genetic information. Whether insurers can use genetic information is at the forefront of these questions. Congress expressly prohibited insurers from using genetic information in health insurance when it passed the Genetic Information Non-discrimination Act in (GINA) in 2008. GINA established an important tone in thinking about how to regulate insurer use of genetic information, but its limited application to health insurance leaves much uncertainty across other lines of insurance. Very few states have implemented restrictions on the use of genetic information in life, disability, and long-term insurance. The overall goal of this project is to consider how states have regulated this use, specifically in regard to restrictions being actuarially justified and how these states have defined actuarial justification.

This paper first discusses the origins of genetic testing and the results that genetic testing provides to illustrate the caution that should be employed in using genetic testing for insurance purposes. With this framework in mind, this paper more specifically addresses the three different areas of life, disability, and long-term. Regarding both life insurance and disability insurance, this paper suggests requiring insurance companies to only use genetic information when actuarially fair. Specifically for life insurance, this includes developing a federal list of predicative testing that allows insurance companies to screen only for high risk, high-penetrance genes. For disability insurance, this paper suggests crafting state level regulation balancing universal access actuarially justified pricing and informed consent for insurer ordered genetic testing. Finally, regarding long-term care insurance, since the market is much less stable than
disability and life insurance markets, a different policy solution is needed. Instead of requiring use be actuarially fair, long-term care suggests an educational partnership policy solution that creates an opportunity for different stakeholders to address the specific needs of long term care insurers and insureds.
I. INTRODUCTION

The advent of private genetic testing in the United States during the 21st Century has greatly increased access to genetic information in ways that have not been possible since the inception of the Human Genome Project (“HGP”) in the late 1980s. The HGP was touted as a “source book for biomedical science in the 21st century and . . . will help us to understand and eventually treat many of the more than 4000 genetic diseases that afflict mankind . . . .”¹ However, what initially began as a Department of Energy project designed to assess the genetic risks of exposure to radiation morphed into a “federally funded, international program to decode the human genome,” thereby laying out the very blueprint for human development.²

As technology improved from the late 1990s through today, genetic testing, which was once relegated to an extremely narrow portion of the population seeking medical treatment, is now readily available to consumers for reasons as diverse as over-the-counter diagnostic purposes and genealogy.³ Furthermore, many of these third-party companies can now reveal genetic risks for diseases such as Celiac Disease, Parkinson’s Disease, and Late-Onset Alzheimer’s Disease, which would have been much more costly at the outset of HGP research and therefore unavailable to many consumers until recently.⁴ Rather than relying solely on health-care providers to test and advise them, patients are now able to receive individualized medical reports (albeit in the form of raw data) from third-party companies that detail and interpret potential genetic flaws which could lead to illnesses.⁵ The costs of these tests range from $69 for 23andMe’s simple ancestry exam to over $2,400 for more detailed, nuanced medical analysis.⁶ All told, genetic testing for defective genes in the United States amounts to an estimated expense of between “$300 million and $670 million annually.”
These tests and their potential to unlock our medical future have attracted public attention in recent years, notably in 2013 when Angelina Jolie revealed that genetic testing showed she carried a “faulty” BRCA1 gene that led to her having a double mastectomy. Ms. Jolie explained that the genetic testing results, combined with her mother’s death from breast cancer, played a decisive role in her decision, and that her doctors reported that her “chances of developing breast cancer . . . [have been reduced] from 87 percent to under 5 percent.” Ms. Jolie noted that the vast reduction in her risk of developing breast cancer gave her a great deal of solace, writing that she “can tell my children that they don’t need to fear they will lose me to breast cancer.”

However, reducing the information contained in our genes to a simple medical equation overstates the value of the information gained in genetic testing, in much the same way a doctor would be unlikely to rely on the results of just one test to diagnose any illness. Most of the defective genes that have been identified so far through research are merely indicators of what could be a potential problem down the road; this function is already served in the insurance industry by family histories of medical conditions. Moreover, even rare diseases which have been definitively linked to defective genes, such as phenylketonuria (“PKU”) can be effectively treated with appropriate diet, exercise, or treatment. While an individual would still be a carrier for that particular gene, any symptoms or complications of the disease would be rendered moot, and for all intents and purposes the information would have little value aside from individual awareness.

Given the prevalence of genetic testing in modern life, and the vast misunderstanding about what the results of a genetic test can tell us about our own medical risks in the future, there are a number of questions regarding how that information should be used and who it should be made available to, especially in light of the impact such information could have on markets such
as insurance. While the Genetic Information Nondisclosure Act of 2008 (“GINA”) and subsequent regulations provide individuals with protection against their genetic information being used against them in the fields of health insurance and employment, genetic test results are not expressly prohibited from usage in other fields of insurance, such as life, long-term care, and disability.

In light of this regulatory gap, genetics labs, consumers, and insurance companies are faced with a multitude of issues which they may not have contemplated when they first entered into their testing agreements: is there enough correlation between genetic markers and the manifestation of a disease to warrant the use of test results? Is the individual information gleaned from genetics testing actuarially sound in determining an individual’s risk? Should government, either state or federal, step in to provide additional protection to individuals who have undergone genetic testing, or should the insurance industry take the lead in developing usage policies? As the volume of private genetic information grows, insurance companies have begun to ask the worth genetic that test results could provide to their business models in fields as diverse as life, disability, and long-term care insurance. To further complicate matters, many insurance companies who specialize in dynamic fields such as long-term care insurance have expressed concern that without access to such information the face certain ruin.

Focusing on the viability of business, though, only addresses one facet in this complicated problem. While other forms of medical testing are more or less directed at the diagnosis and treatment of illnesses, genetic testing in its current state is more focused on identifying potential illnesses or traits which may not even manifest themselves in the individual being tested. Likewise, any discussion about how genetic testing should be used requires an acknowledgment of the baggage of the eugenics movement from the first half of the 20th
century. Moreover, the social, emotional, and psychological stigma of being identified as a carrier of a potentially debilitating trait is overwhelming for many individuals who receive testing—a high price to pay for a process which is likely to yield only indications of diseases that may or may not manifest themselves while failing to account for external influences that might actually cause a disease to manifest itself.\(^\text{14}\)

Therefore, this paper will begin by exploring the origins of the HGP and the ability of genetic testing to accurately predict the occurrence of illness. These considerations are vital to consider when determining whether or not the usage of genetic testing in insurance is both actuarially justified and socially acceptable. The paper will then explore the individual policy concerns and current state of law in the fields of life, disability, and long-term care insurance before making recommendations on the uses of genetic testing within these areas of insurance.


The concept of genetic determination of physical traits has been around for well over a century. For many Americans, this concept is traditionally introduced during primary school science lessons, in which Punnett Squares are employed to illustrate the rudimentary principles of why certain hereditary traits manifest in plants and animals. But it was the explosion in genetic theory and testing capability in the latter half of the 20th Century that led to the intensive analysis of the entirety of the human genome and the role our genetic makeup plays in the development of many human illnesses.\(^\text{15}\)

However, the major U.S. project aimed at mapping the human genome, the HGP, also identified a number of diagnostic shortcomings in the outcomes of testing, as well as a number of ethical concerns about employing genetic test results in fields outside of research. This section presents the context surrounding the advent of the HGP and the issues that were identified during
the U.S. government’s mapping of the human genome. The aim of this section is to illustrate the concerns presented by the use of genetic testing in environments such as insurance underwriting by highlighting the original intent of genetic testing, the outcome of the HGP, and the ethical issues that were identified during the HGP.

The major endeavor in the field of genetic mapping, known as the Human Genome Project in the United States, originated with Watson, Crick, and Franklin’s theory of DNA in 1953. Following developments in DNA sequencing and technology that occurred in the 1970s and 1980s, scientists began to propose the idea of a comprehensive analysis of human genetics as a feasible scientific goal. By 1987, the Department of Energy (“DOE”) became the first U.S. government agency to seize on the advances in genetic testing and develop a program to begin mapping the human genome as a way of assessing “the effects of radiation and energy-related chemicals on human health.” In fact, this push to identify how human health was adversely affected by radioactive exposure, and offer recompense to individuals (especially military veterans) who suffered from illnesses stemming from exposure, was a hallmark of a significant effort by the United States in the 1980s. The timing of these acts by the U.S. government and their stated purpose is crucial to interpreting how genetic testing should be used outside of the scientific community: each of the acts taken by Congress and the executive branch in employing genetic testing was arguably aimed at providing a medical remedy for illnesses or offering financial redress for exposure, and not with an actuarial goal in mind.

In 1988, the National Institutes of Health (“NIH”) established the Office of Human Genome Research in order to “plan and coordinate NIH genome activities in cooperation with other federal agencies, industry, academia and international groups.” This led to an official memorandum of understanding between the NIH and DOE to coordinate their efforts beginning
in 1989, as each organization outlined the expertise they brought to the mapping of the human genome: “the DOE brings extensive expertise in technology development and computer sciences, while the NIH brings a wealth of biological and medical expertise.” As the HGP gained momentum in the 1990s, the project became a multinational effort; it also began to garner attention from private industry, who saw potential for monetization of genomic testing and its byproducts, especially after the initial findings (over 90% of the human genome sequence) of the HGP were published in February 2001. The completed genomic map that was presented in the early 21st Century was a composite map of many individuals, and despite some critiques that using such a patchwork approach would fail to address the “great variability between individual human beings,” the HGP presumed that humans share enough “functionally important DNA” to make any genetic defects identified relevant across the entire species.

Developing concurrently with genetic mapping were a number of ethical and legal concerns that arose out of genomic discoveries. Despite the notion that “[a] genetic predisposition for almost any disease knows no boundaries based upon race, color, religion, sex, or national origin,” individuals involved with the HGP identified a number of concerns arising out of genetic testing including: privacy issues for individuals and their families post-testing, past misuses of genetic information, genetics leading to a new eugenics movement; and the “potential unfair genetic discrimination in insurance.” However, one additional question that the HGP failed to address, and that Congress has since failed to fully reckon with despite prohibiting the use of genetic testing for health insurance purposes, is what the ultimate goal of genetic testing should be: should the purpose of the HGP be seen to provide mankind with a significant platform for continued research and medical advances, or should companies be able to profit from public research and the genetic contributions of individuals tested?
This question is vital in light of the fact that numerous private companies have rushed to patent genetic discoveries in the wake of the HGP’s published results, demonstrating that a market that exists for the data uncovered by genetic testing.\textsuperscript{31} And while the explosion in offshoots of genetic testing, such as cloning and stem-cell research, have seen regulations in funding and testing imposed by the NIH,\textsuperscript{32} there appears to be an absence of similar restrictions on genetic testing. While this potentially allows private companies to advance their research at an accelerated rate, it poses a much greater risk that individuals’ information might be misused or their privacy may be violated without their knowledge.

Of even more vital interest—and a point that seemingly goes unaddressed in the rush to justify the expenditure of the HGP—is whether or not the findings of the HGP can provide sound evidence that specific genes can fairly and accurately predict the likelihood of illnesses appearing. This issue is even more relevant if the information uncovered by genetics testing does little to advance our understanding of illnesses and their genesis, at least to a degree above the information insurance companies already collect as part of their application process, such as family histories. Despite the expectation that the HGP could, by mapping and sequencing the human genome, provide “fundamental information needed to further our basic scientific understanding of human genetics and of the role of various genes in health and disease,”\textsuperscript{33} the actual interplay of genes and environmental factors remain largely obscured at the project’s conclusion:

When the HGP is finished . . . the complete inventory of genes and the full sequence will represent an immensely valuable source book for biology and medicine. We will not know, however, the function of genes in isolation, let alone in concert; we will not know how they are regulated; we will not know the worldwide variation in the genes among the some six billion persons who will inhabit the globe by that time; and we will not know the complex relationship between variation in genome constitution and variation in phenotype.\textsuperscript{34}
Given that the HGP’s initial work fell short of providing clear correlations between faulty genes and the manifestation of disease—and given the overarching implications to individual privacy—it is necessary to address whether the developments in genetic testing and diagnostics since the publication of the HGP’s results have provided any additional support for the connection between genetics and actual illness.

B. Do Genetic Test Results Sufficiently Correlate with Illness?

Before addressing the ethical concerns identified by the HGP, it is important to consider what the HGP and on-going genetic testing actually tells us about illnesses and their likelihood of manifesting. In order for genetic testing to serve any purpose for insurance companies, there must first be an analysis of whether or not the data provided by such tests actually provides insurers with actionable, individualized information: will the results of genetic testing allow insurance companies to more accurately gauge an individual’s risk within a particular insurance category, and offer a fair and profitable insurance rate as a result? While insurance companies have traditionally been permitted to use medical testing in determining rates and underwriting, those tests have been confined to exams which have a diagnostic purpose or involve a family history of symptoms that have manifested, and are not merely based on indications of illnesses that might manifest themselves at some point along a genetic lineage.

Various policies, especially life, long-term care, and disability insurance, have differing concerns in regard to two key considerations of insurance: mortality and morbidity costs. While the “information . . . obtained from the HGP is neither intrinsically good nor bad” and will rely on how society determines it should be used, public health history in the United States—especially in the area of eugenics and the response to HIV/AIDS—gives us reason to
pause and reflect on whether genetic testing actually serves an actuarial purpose prior to allowing for its use.

In other words, while genetic testing for any one individual will likely produce results that indicate potential “abnormalities” in their genome, should society allow those “abnormal” genes be used to accurately predict the occurrence of illness in the future? Or, as in the case of many “genetic” illnesses, are there simply too many variables—including lifestyle choices and exposure to injurious materials—to warrant using genetic testing in a manner that is actuarially justified? This is especially pertinent in light of the fact that many individuals outside of scientific fields have difficulty understanding the nuances of genetic markers and environmental factors, and more importantly the absence of guidance on who gets to interpret the results of genetic testing in the insurance realm.

This section will begin by briefly illustrating how past public health issues, namely eugenics, have shaped our understanding of how genetics factors into human development and how modern thinking regarding the inheritance of genes parallels the eugenics logic present in such cases as *Buck v. Bell*. This section will then use the framework of the 1980s and 1990s HIV/AIDS epidemic to illustrate the harmful effects of social ignorance of genetics and to provide a model response that could be helpful in safeguarding individuals who undergo genetic testing. Finally, this section will analyze the extent to which genetic markers alone can accurately predict the occurrence of illness, or if the majority of genetic markers are simply too attenuated from illness to make them much use for insurance purposes.

1. **Undercurrent of Eugenics in Modern Genetic Testing**

   The history and ideology of eugenics is outside of the scope of this paper, yet its notion that genetic heredity is determinative of the development and outcome of an individual’s life
continue to influence discussions of the role genetic testing should play in modern society. While this paper does not conflate eugenics with genetic testing, it is necessary to briefly address the language and ideas that stem from eugenics as a means of realizing the full implications of using genetic test results in regard to individuals.\textsuperscript{43} Eugenics is defined as a theory that gives “more suitable races or strains of blood a better chance of prevailing speedily over the less suitable than they otherwise would have had” by selecting and advancing “natural gifts in a way that would be advantageous to future generations.”\textsuperscript{44} Adding to the baggage presented by eugenics and sterilization laws in the United States in the 20th Century is the fact that many of these laws influenced dozens of nations around the world, including Nazi Germany, who passed similar laws.\textsuperscript{45}

Statutes supporting eugenics—or disparaging those that society considered less desirable by preventing their ability to reproduce—found expression and acceptance in the infamous case of \textit{Buck v. Bell} in 1927: a case which has never been expressly overruled by the Court since. Carrie Buck was an allegedly “feeble-minded woman” whose mother and grandmother were also identified by the U.S. Supreme Court as “illegitimate” and “feeble-minded.” and the Court highlighted a state’s responsibility to protect public health as a key reason for upholding the constitutionality of the Virginia statute that permitted sterilization in certain instances.\textsuperscript{46} However, of greater concern to the modern field of genetic testing is the Court’s dicta in explaining its reasoning:

\begin{quote}
We have seen more than once that the public welfare may call upon the best citizens for their lives. It would be strange if it could not call upon those who already sap the strength of the State for these lesser sacrifices, often not felt to be such by those concerned, in order to prevent our being swamped with incompetence. It is better for all the world, if instead of waiting to execute degenerate offspring for crime, or to let them starve for their imbecility, society can prevent those who are manifestly unfit from continuing their kind.\textsuperscript{47}
\end{quote}
This reasoning presented by the Court—which could be considered inactive or antiquated, but is still “good” law—would seemingly imply that a state’s ability to protect “healthier” genes could allow for some measures to be introduced that would limit the ability of faulty genes to be passed on.\textsuperscript{48} Or, alternatively and more likely, the presence of faulty genes in an individual’s genome could be used to justify limiting access to goods and services within society. Despite being generally sidelined as a serious field of science following the end of World War II, eugenics continues to hold a place in legal thinking throughout the 20th Century that has since manifested itself in the genetics discussion.\textsuperscript{49}

Within each area of insurance law addressed in this paper—life, disability, and long-term care—the considerations for whether to employ all, some, or no genetic information require a more detailed analysis that will be provided in the following sections. This paper merely advances the recommendation that the specter of eugenics should serve as a warning that the use of genetics in any field should thoroughly consider the ramifications of usage not just to those seeking to profit from it in some way.

2. **HIV/AIDS as Model for Genetic Testing.**

Even with the additional understanding provided through knowledge of eugenics in the United States, it can be difficult to imagine the full range of consequences or issues that go into using genetic testing outside of research without an analogous set of circumstances. These issues include: dealing with relatively unknown conditions for various illnesses; the lack of broad social support or counseling for those who get tested; the potential for social stigma to attach to those who express certain traits; and the lack of treatment options for those diagnosed with faulty genes. Genetics also poses a unique problem in that the possibilities of discovery encompass so many aspects of human health and society, and continuing research is needed to fully draw out
the interplay of genetic and environmental factors. Especially concerning are instances where “[u]nfair genetic discrimination in insuring can occur simply because of insurer ignorance in granting statistical validity to genomic data that is not sufficiently precise for that purpose.”

However, there has been at least one public health crisis in the late 20th Century that presents similar issues to genetic testing, and that is the HIV/AIDS crisis in the 1980s and 1990s in the United States. As this part will illustrate, the HIV/AIDS crisis provides effective guidance on the initial shortcomings in response to a major medical issue and also provides some suggestions on how society could safeguard genetic information while allowing for its usage outside of research. Unlike genetic testing, the response to HIV/AIDS in the early 1980s in the United States was centered on determining who carried the virus and then preventing individuals from acquiring the virus from those who were infected. The model that eventually developed for dealing with HIV/AIDS differs from genetic testing in one crucial aspect: HIV testing was in response to a particular set of symptoms that would eventually cause death as the illness progressed.

Although these differences appear to be very clear cut and addressable, the initial response bordered on mass paranoia and quarantine at times, especially in the time before the virus was actually identified. Further complicating the problem of HIV/AIDS was that there was no mandated support or counseling for those who were tested or those who tested positive. Those who tested positive for HIV were ostracized from society: “the disease was discussed in hushed voices and few wanted to understand much less embrace the affected members.” Finally, there was very little government involvement in making treatment generally available to those affected by HIV until 1989, leading to even greater social stigma and public health consequences as the United States attempted to respond to the disease.
In the late 1980s, though, many states began to take steps to reduce the social stigma of HIV/AIDS, increase access to treatment, and provide support to those diagnosed with the virus. One of the most comprehensive statutes adopted within the United States was in New York, who in 1988 recognized the need to provide comprehensive protection and confidentiality to individuals who underwent testing for HIV, as well as those who tested positive.  

Public Health Law §2781 was amended to address issues of informed consent for HIV testing, but also required that:

At the time of communicating the test result to the subject of the test, a person ordering the performance of an HIV related test shall provide the subject . . . with counseling or referrals for counseling: (A) for coping with the emotional consequences of learning the result; (B) regarding the discrimination problems that disclosure of the result could cause; (C) for behavior change to prevent transmission or contraction of HIV infection; (D) to inform such person of available medical treatments . . . .

While treatment options for HIV/AIDS have improved since HIV testing and disclosure laws were passed across the United States, and the social stigma of acquiring HIV/AIDS has been somewhat reduced, New York’s statute dealing with HIV-related testing could serve as a model for genetic testing and subsequent results. Although, genetic testing does not seek to address the same concerns as HIV testing, many of the same concerns about social stigma and treatment pertain to genetic testing in similar ways to HIV. There are ways to treat the symptoms of genetic-related illnesses, but there are currently no means of actually “curing” faulty genes outside of experimental treatments, leaving those diagnosed with a lifetime of treatment but no remedy. Therefore, genetic counseling, much like HIV counseling, serves an important function by allowing for a more gradual, supportive adjustment to life with an illness and also
provide those who are living with genetic conditions to effectively seek out resources to manage their symptoms.\(^6\)

The emergence of statutes like New York’s illustrates the need for governments to step in early in the process of testing and research and provide guidance or regulations to providers and testing labs, rather than watching as medical personnel attempt to stumble through ethical and legal concerns.\(^6\) Although the HGP results have been in the public domain for over a decade now, it is not too late for state or the federal government to provide safeguards similar to New York’s for individuals who undergo genetic testing, and as further research uncovers more genetic ties to illness, the need for genetic counseling, treatment options, and protection against discrimination become more relevant.

3. **Genetic Test Results and Actuarial Justification.**

Ultimately, though, the discussion surrounding genetic testing boils down to actuarial justification and whether genetic testing can tell us anything more than what is already collected: “[t]he distinction of statistical probability from absolute conclusiveness is important when one explores the issues of economic and social policy in health insurance underwriting, which may, in turn, depend upon the accuracy of genetic testing.”\(^6\) This is even more important in the area of insurance, as many individuals outside of the scientific community often mistake the significance of genetic markers for advances in treatment or believe that a potential cure is close at hand.\(^6\) In fact, there has already been a degree of genetic analysis arising in insurance in the form of family histories, which can be seen as little more than “low-tech” genetic testing.\(^6\) Therefore, this section explores whether the claim that genetic markers indicate an individual’s
predisposition for a certain illness is a valid statement or whether there should be additional considerations in the areas of insurance this paper deals with.

The various manners in which genes contribute to the development of genetic diseases range from illnesses that manifest from a single genetic defect (such as Huntington’s Disease or phenylketonuria) that will manifest in the carrier no matter what lifestyle choices they make, to non-inherited diseases such as many cancers that stem from genes that have mutated during an individual’s lifetime based on that individual’s actions or exposures to toxins. In between these two extremes lie diseases which have a mixture of genetic causes and environmental factors which have been difficult to pin down in precise ways.

The illnesses that stem from a single genetic defect have a particular attraction to the insurance industry, as they fit more into the general idea of actuarial justification: the presence of a defective gene indicates the eventual emergence of an illness. However, for other illnesses which have an identified genetic component but also require multifactorial analysis to more accurately predict the probability of that illness presenting in an individual, the answer is not as simple.

Traditionally, health testing, even for insurance purposes, has been premised on the notion that the results could point to a diagnosis of an actual illness, and that diagnosis which manifested in actual symptoms served to actuarially justify a higher rate based on the individual. However, outside of illnesses which manifest as the result of a single genetic defect, additional medical testing would likely be needed to place any value on the result of the genetic test and this could quickly become cost prohibitive for companies. Likewise, it could cause individuals to forgo genetic testing altogether if they
are subjected to an additional battery of tests or questions to further hone the results of genetic testing.

Furthermore, given the disparity between the public’s perception of genetic illnesses and the reality that there are few genetic defects that will trigger illness, there is the risk that insurance companies and consumers could misinterpret genetic results, such as mistaking a mere carrier of a genetic defect for an individual who will certainly manifest symptoms. This failure to understand the application of scientific discovery is inherent in most medical breakthroughs, but companies who rely on genetic results to set rates or underwrite insurance policies might drive consumers away as the result of setting rates higher than they actuarially should be. Finally, with traditional diagnostic tests for illnesses such as heart disease, there is a strong possibility that such testing can be used to outline treatments that an individual can follow to improve their health, and likewise their insurance rate; with genetic testing, there is currently too little information available to provide any treatment for genetic defects that are more likely to manifest, and the genetic defects that are unlikely to manifest are too poorly understood to offer specific recommendations.

While there may be actuarial justification for allowing insurance companies to have limited access to genetic testing that more definitely illustrate the emergence of a genetic illness, genetic research to this point appears to be too incomplete to allow for broad usage of genetic testing without additional safeguards for individuals. The examples of safeguards provided in this paper would greatly assist in protecting consumers from adjusting to life with a genetic illness or predisposition for illness, but given the inconclusive nature of individual genetic testing, any use of genetic information
that lacks the definition found in Huntington’s Disease or phenylketonuria could have negative consequences for consumers and insurers depending on the specific field of insurance being considered.\textsuperscript{74}

C. Privacy Concerns.

Finally, assuming genetic information gleaned from testing is actuarially justified, should an individual’s right of privacy or need to provide informed consent outweigh an insurance company’s desire to have access to individual genetic test results? While some states have passed laws that prohibit insurance companies from requiring an individual to undergo a genetic test,\textsuperscript{75} there is still the issue of whether or not an insurance company should have access to the results of a test that an individual may willingly undergo for other reasons. Furthermore, there are also issues of whether or not an individual’s personal genetic test results should be allowed to apply to her progeny, as genetic testing carries with it far-reaching consequences for descendants of persons who might test positive as carriers for genetic defects.\textsuperscript{76}

This section briefly outlines some considerations that should be made with regards to an individual’s right to privacy and furnishing of informed consent prior to employing genetic test results in the fields of life, disability, and long-term care insurance.

1. Right to Privacy and Genetic Testing.

The Supreme Court has previously recognized the right to refuse medical treatment\textsuperscript{77} and that “the right to decisional privacy are of sufficient importance to deserve constitutional protection.”\textsuperscript{78} However, this right to refuse treatment has not been extended to encompass a right to refuse disclosure of genetic test results, and the privacy
protections outlined in *Griswald* have never been extended by the Court to issues such as genetic testing and the results of individual genetic tests. Furthermore, in some states there have been rulings that individuals have no right to privacy or ownership of the results of their tests, or even subsequent medical advancements born from an individual’s genetic material.\(^7\) This is even more important to consider given the uneven bargaining power between a physician relaying genetic testing results and an individual who may not understand the degree of genetic interpretation required in many instances.\(^8\)

Given the Court’s relative silence on the issue of a genetic right to privacy, and the potential for state governments to interpret a right to privacy in differing ways absent direction from the Court, it may be more effective to consider another avenue that might dictate whether or not an individual’s information could be disclosed: the doctrine of informed consent.\(^9\)

2. **Informed Consent and Genetic Testing.**

The main struggle within a notion of informed consent is that the stated goals of the procedure are: does the procedure serve to treat an illness, or is it merely for diagnostic purposes?\(^10\) This struggle is highlighted even more by the fact that individuals usually undergo testing for the purpose of obtaining some form of health benefit, rather than merely being told that they have a defect which cannot be treated, as is often the case with genetic testing.\(^11\)

Traditional informed consent, generally speaking, must contain an explanation of what a procedure is addressing, what the expected outcome is, and the potential risks of things going wrong during the procedure.\(^12\) However, genetic testing displays how inadequate these traditional tenets are in the face of test results which may completely fail
to diagnose any actionable results—or might even condemn an individual’s descendants to higher scrutiny due to the possibility of inheritance. Genetic testing and its results naturally beg the question, albeit somewhat absurdly, of whether an individual can provide informed consent for subsequent generations, or whether informed consent is meant to warn against every single possible risk that may or may not contribute to a potential genetic defect. Therefore, states or the federal government should explore new means of providing a new doctrine of informed consent to compensate for the unique aspects of genetic testing.

While many of the concerns discussed in this section seem to be merely hypothetical in nature, exploring the interplay of actuarial justification and social concerns in specific insurance areas will help to illustrate the potential risks and rewards of employing genetic testing for ratemaking and underwriting purposes, beginning with life insurance.

II. Insurer Use of Genetic Information in Life Insurance

A. What Is Life Insurance:

A life insurance policy is a contract with an insurance company in which the insured makes premium payments in exchange for a lump-sum payment, known as a death benefit, to beneficiaries upon the insured's death. In regard to regulations on use of genetic information, life insurance must be treated differently than other forms of insurance, such as long-term care and disability insurance for a number of reasons. First, unlike disability and long-term care insurance, life insurance is often viewed as a commodity rather than a necessity. As stated above, its primary purpose is to compensate the beneficiary, not provide the insured with the means to get adequate care. In that sense, long-term care and disability insurance are more
similar to health insurance, as it is needed and used by the insured during their life. Rather, life insurance is often viewed as more of an investment. For example, permanent life insurance is an investment for the policy holder as it allows the policy holder to accumulate cash value.\textsuperscript{89} On the other hand, both term and permanent life insurance are considered an investment in the financial security of the beneficiary, often a policyholder’s family or dependents.\textsuperscript{90} For these reasons, state regulation for the use of genetic information may be different, and perhaps not as stifling as long-term care and disability insurance. This section will focus on policy suggestions for regulations on the use of genetic information tailored specifically to the unique aspects of life insurance. The following sections will address the use of this information in the areas of disability and long-term care insurance.

Access to genetic information by life insurers has been a hotly contested topic of discussion for many years.\textsuperscript{91} Genomic knowledge is quickly developing and life insurers’ use of genetic information is of substantial importance due to the increase in predictive testing for disorders in clinical practice. The possibility of using genetic data to underwrite an applicant's insurance policy or set higher rates has given rise to concerns about the emergence of “genetic discrimination.”\textsuperscript{92}

To combat these concerns, a number of states have enacted statutes limiting the use of genetic information by life insurers.\textsuperscript{93} However, since there is no federal legislation governing genetic testing and the use of this information, states are free to create their own legislation in this area and thus, state approaches to insurer use of genetic information vary greatly, from no restrictions at all to a prohibition on discriminating based on certain genes.\textsuperscript{94}
B. **Current State Regulations in Life Insurance:**

Despite the growing concerns of insurer’s use of genetic information, and the increasing proliferation of genetic testing and results, there has been little legislation, and hardly any litigation, of the use of this information for purposes of underwriting. In fact, fewer than half of the states address life insurer’s use of genetic information in enacted statutes, each approach varying in protection. Additionally, there are no NAIC model laws or regulations providing guidance on the use of genetic information for purposes of life insurance.

The firmest restrictions on the use of genetic information by life insurers are found in California. This statute states that no insurer shall require a test for the presence of a genetic characteristic for the purpose of determining insurability other than for those policies that are contingent on review or testing for other diseases or medical conditions. Furthermore, informed consent is required for all genetic testing. However, a life insurer still has the right to decline an application or charge higher rates on the basis of a manifestation of a disease or disorder. Several other states prohibit life insurers from performing or ordering a genetic test without the applicant’s written consent, however, states vary even in requirements of written consent. In New York, Oregon, Minnesota, and Colorado a life insurance company that requires or asks for a genetic test for purpose of determining insurability must first obtain the applicant’s written consent. However, Indiana requires this written consent in other areas of insurance, but explicitly excludes life insurers from requiring the applicant’s written consent in using genetic information. New York further requires that, in the event that an insurer’s adverse underwriting decision is based in whole or in part on the results of a genetic test, the authorized insurer shall notify the individual of the adverse underwriting decision.
Other states prohibit a life insurance company to refuse the issuance of a policy based on certain traits. For example, North Carolina forbids an insurance company to deny a policy or charge higher premiums based solely on the fact that the applicant possesses sickle-cell trait or the hemoglobin C trait.\textsuperscript{103} Similarly, in Florida, an insurer may not refuse to issue a life insurance policy or impose higher premiums based solely on the fact that the applicant has the sickle-cell trait.\textsuperscript{104} Additionally, California prohibits life insurers from discriminating based solely on the fact “that the person to be insured carries a gene which may, under some circumstances, be associated with disability in that person’s offspring, but which causes no adverse effects on the carrier. Such genes shall include, but not be limited to, Tay-Sachs trait, sickle cell trait, thalassemia trait, and X-linked hemophilia A.”\textsuperscript{105} Finally, some states offer very little protection. For example, in New Hampshire, the statute merely requires that a life insurance company with obtained genetic information, whether obtained through voluntary testing or other means, may only use that information in writing coverage for life insurance, and not in writing other insurance coverage.\textsuperscript{106}

A number of states, have enacted stricter laws for the use of genetic information for purposes of writing life insurance, mainly, requiring that the use of the information be actuarially justified. The NAIC, in regulating rates in health insurance, defines actuarial justification as, in markets with actuarially justified rating requirements, insurers must demonstrate a correlation between case characteristics and increased medical claims costs.\textsuperscript{107} The statutes requiring actuarial justification for the use of genetic information in life insurance are included in the chart below. These statutes are grouped together because the restrictions, in requiring the use to be “reasonably related to the risk” or prohibiting unfair discrimination, is essentially mandating that the use of this information be actuarially justified. However, despite the definition provided by
the NAIC, disparities may exist even, such as how distinct this “correlation” need be. This contributes to the lack of clarity that exists in determining what actuarial justification means in each state definition.

<table>
<thead>
<tr>
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<th>Statute</th>
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<tr>
<td>Arizona</td>
<td>Ariz. Rev. Stat. Ann. § 20-448(E)</td>
<td>“The rejection…or the determining of rates, terms or conditions of a life…insurance contract on the basis of a genetic condition…constitutes unfair discrimination, unless…actuarial projections establish that substantial differences in claims are likely to result from the genetic condition.”</td>
</tr>
<tr>
<td>Kansas</td>
<td>Kan. Stat. Ann. § 40-2259(d)</td>
<td>“an insurer writing life insurance coverage…may not…provide for rates or any other aspect of coverage that is not reasonably related to the risk” (regarding use of genetic information).</td>
</tr>
<tr>
<td>Maine</td>
<td>24A Me. Rev. Stat. Ann. § 2159-C(3)</td>
<td>&quot;An insurer may not make or permit any unfair discrimination against an individual in the application of genetic information…in the issuance…of an insurance policy for life...”</td>
</tr>
<tr>
<td>Maryland</td>
<td>Md. Code Ann., Ins. § 27-208(a)(3)</td>
<td>“Unless there is actuarial justification, an insurer may not refuse…or allow a differential in ratings, premium payments, or dividends in connection with life insurance and annuity contracts solely because the applicant or policyholder has…” certain genes</td>
</tr>
<tr>
<td>Massachusetts</td>
<td>Mass. Gen. Laws Ann. Ch. 175, § 120E</td>
<td>“No insurer…shall practice unfair discrimination against persons because of the results of a genetic test or the provisions of genetic information…”</td>
</tr>
<tr>
<td>Montana</td>
<td>Mont. Code Ann. § 33-18-206(4)</td>
<td>“No person shall make or permit any unfair discrimination…for any contract of life insurance…” “The rejection…or the determining of rates, terms or conditions of a life…insurance contract on the basis of a genetic condition…constitutes unfair discrimination, unless…actuarial projections establish that substantial differences in claims are likely to result from the genetic condition.”</td>
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<td>New Jersey</td>
<td>N.J. Stat. Ann. § 17B:30-12(f)</td>
<td>&quot;No person shall discriminate against any individual on the basis of genetic information or the refusal to submit to a genetic test…”</td>
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<tr>
<td>New Mexico</td>
<td>N.M. Stat. Ann. § 24-21-4 (C)</td>
<td>Use of genetic information is permissible “if the use of… genetic information for underwriting purposes is based on sound actuarial principles…”</td>
</tr>
<tr>
<td>Vermont</td>
<td>Vt. Stat. Ann. tit. 18, § 4724(3)</td>
<td>Prohibiting “permitting any unfair discrimination… based on medical information, including the results of genetic testing…”</td>
</tr>
<tr>
<td>Wisconsin</td>
<td>Wis. Stat. Ann. § 631.89</td>
<td>“an insurer writing life insurance coverage…may not…provide for rates or any other aspect of coverage that is not reasonably related to the risk involved” (when using genetic information).</td>
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</table>
1. **Defining Actuarial Justification:**

   Among these states that prohibit “unfair discrimination”, it is difficult to ascertain a uniform definition of unfair discrimination or actuarial justification. Many of the jurisdictions which require actuarial justification do not define the term, or the term unfair discrimination, at all. Those that do, have numerous ways of defining the term and are listed in the chart below.

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</tr>
<tr>
<td>Maine</td>
<td>24A Me. Rev. Stat. Ann. § 2159-C(3).</td>
<td>Unfair discrimination” includes, but is not limited to, the application of the results of a genetic test in a manner that is not reasonably related to anticipated claims experience</td>
</tr>
<tr>
<td>Massachusetts</td>
<td>Mass. Gen. Laws Ann. Ch. 175, § 120E</td>
<td>“Unfair discrimination” is any action not “taken pursuant to reliable information relating to the insured’s mortality or morbidity, based on sound actuarial principles or actual or reasonably anticipated claim experience.”</td>
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<tr>
<td>Montana</td>
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<td>New Jersey</td>
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<td>New Mexico</td>
<td>N.M. Stat. Ann. § 24-21-4 (C).</td>
<td>“Unfair discrimination” is any action not “taken pursuant to reliable information relating to the insured’s mortality or morbidity, based on sound actuarial principles or actual or reasonably anticipated claim experience.”</td>
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<td>Vermont</td>
<td>Vt. Stat. Ann. tit. 18, § 4724(3).</td>
<td>There is no unfair discrimination where there is a relationship, based on actual or reasonably anticipated experience, between the medical information and the cost of the insurance risk that the insurer would assume by insuring the proposed insured.</td>
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The state statutes defining unfair discrimination or actuarial justification do so in a circular fashion, describing unfair discrimination as underwriting or rate-making not based on “actuarially sound principles and reasonably anticipated claims experience” but failing to describe what actuarially sound principles are or what constitutes “reasonable claims experience.” Likewise, the Kansas and Wisconsin statutes which require the rates and coverage to be “reasonably related to the risk” fail to define “reasonably related.” More troublesome is the fact that all of these terms have yet to be litigated in most of these jurisdictions. Cases are not being litigated about the use of genetic information in the realm of life insurance, and particularly, about the definition of actuarial justification within the states that require it for use of genetic information. Whether that is indicative of insurers not violating these statutes or of policyholders’ unawareness that insurers may be violating the statutes is unascertainable at this time. Finally, state insurance commission offices admit that the office either does not have any regulations on the use of genetic information in life insurance, or is unaware of any regulations or legislation restricting this use.

However, many of these states do use and define the term “actuarial justification” in other statutes regulating different areas of insurance, such as automobile insurance. For example, in Maryland, an insurer may provide a reduction in rates in automobile insurance “based on actuarial justification to an insured who…is at least 55 years old and…has completed successfully a course in accident prevention.” In litigating the definition of “actuarial justification” in this statute pertaining to automobile insurance, the Maryland Court of Appeals, the highest court in Maryland, defines actuarial justification as requiring “some demonstrable correlation between the factor and the loss experience of the group of insureds showing that common factor.” However, even trying to use a litigated definition of actuarial justification
for guidance, albeit in a different area of insurance, provides little, if any, clarity in ascertaining a uniform definition of actuarial justification for purposes of life insurers’ use of genetic information. Again, this definition provided by the Maryland court gives little to no clarity on how close a correlation need be or how great a loss must occur.

The lack of a uniform definition across states, and more specifically, the lack of clarity in the definition, is particularly problematic for consumers and potential applicants. The states’ often circular definitions contribute to the knowledge disparity between insurers and consumers. Consumers may often be unable to determine whether life insurance companies may use their genetic information, how this information may be used, and if coverage could be extended or not. Confusion may exist among insurance companies as well. Without a concrete definition of actuarial justification, life insurance companies and their employees have wide discretion in determining whether or not using genetic information is actuarially justified, which can lead to arbitrary definitions of these terms and less coverage. Further, if each states defines “actuarially sound principles” differently, there is no uniformity among national insurance companies. This leads to arbitrary “correlations” and uncertainty among consumers as to if and when insurance companies may use this information.

C. Policy Recommendations for the Use of Genetic Information in Life Insurance

The core purpose of life insurance is to allow people to share the financial risks of a premature death. As in all insurance, the larger the pool of policyholders who share the risk, the more likely it is that the pool reflects the risk of the population as a whole, and thus, the more fairly premiums can be calculated. However, the expansion of predictive genetic testing threatens to complicate actuarial risk assessments.
Life insurance may be viewed as an indispensable social good, fulfilling the goals of preventing disruption and economic instability in the family of a decedent and preventing the impoverishment of a family following the death of the “breadwinner.” If this is the purpose of life insurance, the most important goal should be ensuring coverage to as many as possible, both high-risk and low-risk individuals and a policy solution should be framed around these stakeholders. However, some view life insurance as an economic commodity rather than a social right. Under this model, ensuring the survival and prosperity of insurance companies is of utmost importance in issuing life insurance policies and a policy solution must be framed around the insurance companies. Finally, other policy considerations must be taken into account in determining a potential solution including the privacy of the applicants, political impacts and the ease of implementation, and other stakeholders, such as health insurers and health care providers as these stakeholders will ultimately affect the policyholder.

1. **Why Actuarial Justification Should be Required:**

In determining a potential policy solution, it is beneficial to consider the two extreme of this policy debate that is, requiring no regulation of the use of genetic information in life insurance and requiring a complete prohibition of the use. By considering these two extremes, it is clear that a middle ground approach, requiring that the use of genetic information be actuarially justified, is an appropriate policy solution, as it best balances each different stakeholder’s interest.

a. **Complete Prohibition of the Use of Genetic Information**

This policy approach views life insurance as a social good and favors coverage for the consumers. First, considering the policy from the consumer standpoint, this policy solution is ideal for high-risk individuals. Those individuals that receive genetic testing and discover gene
mutations, predispositions to diseases, and other increased risk will be more likely to purchase life insurance policies. Without disclosing the information of their genetic tests, these high-risk individuals would not have to worry about being discriminated against or denied due to a genetic predisposition. This policy recommendation will increase overall life insurance coverage, especially among these high-risk individuals. Furthermore, privacy concerns are not at risk.

However, this policy suggestion is not without its economic shortcomings. Insurance companies are severely disadvantaged by this policy approach. When the consumer knows more than the insurer, known as information asymmetry, adverse selection occurs, meaning that more high-risk individuals are seeking life insurance than low-risk individuals. When higher risk individuals disproportionately seeking insurance, the risk is not being fairly pooled and shared among the “population” as is ideal. Since more high-risk individuals are covered and insurance companies are paying out more claims. Adverse selection, in turn, may lead to increased premiums. Increased premiums often cause the low-risk insureds to drop out as they no longer want to pay expensive premiums for their low risk. As this trend continues, with more high-risk applicants getting coverage and low-risk insureds dropping out, coverage could become too expensive, causing life insurance companies to go out of business. The economic implications of a complete prohibition on the use of genetic information in life insurance could be devastating to insurance companies.

However, health insurers and medical providers could benefit from a prohibition on use of this information. Without fear of being unfairly discriminated against in life insurance, such as denying coverage or increasing rates that are not actuarially justified, potential applicants will be more willing to do genetic testing. With increased genetic testing, applicants may find preventive diseases and seek out preventative measures rather than waiting to be diagnosed for preventable
diseases. For examples, actress Angelina Jolie discovered she had a gene mutation that markedly raised her risk of breast cancer and underwent a preventative double mastectomy. Discovering these diseases early can limit medical costs paid by health insurers rather than waiting to treat the disease. Additionally, this could benefit life insurers by keeping policyholders alive longer by discovering genetic predispositions before the disease manifests and taking preventative steps.

b. No Restrictions on Use of Genetic Information in Life Insurance

The policy solution of complete access and use of genetic information views life insurance as an economic business commodity rather than a social good or entitlement. Since, under this framework, the purpose of life insurance is economic benefit, maximizing coverage is not the primary goal of insurance, but rather, protecting the life insurance companies’ financial viability. Considering this policy from the consumer’s standpoint, high-risk applicants are severely disadvantaged and susceptible to denial of life insurance applications due to a genetic predisposition or disease. Many will go without coverage. However, this solution may be beneficial for low-risk individuals, who will likely end up paying more actuarially fair premiums. Furthermore, many consumers may be misinformed about when their genetic information may be used. For example, a recent study shows that 23% of people who knew about GINA, the Genetic Information Nondiscrimination Act, incorrectly thought that the Act provided protection from discrimination in life, disability, and long-term care insurance as well. With this incorrect information, applicants may be more willing to submit to genetic testing erroneously thinking their information will be protected from all insurance companies, only to be denied due to genetic test results when applying for life insurance.

As for insurance companies, this policy solution is ideal to limit policy payouts and maximize company profitability and viability. By eliminating information asymmetry and
adverse selection, life insurance companies will use genetic information to underwrite and either deny or charge higher premiums to high-risk individuals. By denying these individuals, insurance policy payouts will be smaller and less frequent, maximizing profit for the life insurance companies. Insurer knowledge of an applicant’s genetic propensities could predict risks more accurately, however, this could lead to insurer’s overestimating risk. 125 This might occur because insurance, with lack of medical knowledge and information, may be unaware of a particular gene’s mortality rate or even a likelihood of manifesting symptoms. Often, genetic literature tends to be skewed by studying only severely affected patients, rather than reflecting more reliable population-based data. 126 Therefore, insurers may overestimate the risk of an individual applicant which could price many, even lower-risk individuals, out of the life insurance market. 127

This policy solution could also be detrimental to health insurance companies, health care providers, and, in the long run, life insurers. When applicants are discouraged from genetic testing, they may fail to detect preventable diseases, which racks up more costs for health care, and potentially causes premature death. Fear of discrimination may prevent some people from participating in genetic testing or studies that explore the real-world consequences of utilizing genomic information. 128 For example, in the ongoing MedSeq Project, a trial in which the results of whole-genome sequencing are electronically stored in participants' medical records and patient and physician outcomes are tracked, 25% of prospective participants declined participation due to fear of insurance discrimination. 129

2. **Requiring Use of Genetic Information Be Actuarially Justified: Seeking and Using Only High-Risk, High-Penetrance Genes and Variants**

Some states have started to pass restrictions on the use of genetic information in life insurance, concluding that insurers must avoid “unfair discrimination.” But as noted above,
questions then arise of how unfair discrimination and actuarial justification should be defined. This policy recommendation is to require insurance companies to only use genetic information when actuarially justified and have a federally implemented, consistent definition of “actuarial justification.” This policy suggestion proposes that the actuarial justification be as insurers being able to seek and use genetic information only to find specific high-risk, high-penetration genes and variants. Penetrance in genetics is defined as the percentage of individuals with a given gene or genotype who exhibit the particular trait associated with that gene. Therefore, this definition of actuarial justification requires life insurers use genetic information to find only genes that have a high risk of mortality and have a high percent chance of that risk, that particular trait, manifesting in the applicant.

Having this narrower definition of actuarial justification is preferable to the traditional definition of actuarial justification, traditional being simply demonstrating a correlation between specific genes and characteristic and increased risk leading to denial or higher premiums. With the requirement of a “correlation” being undefined in scope, this traditional definition of actuarial justification will likely lead to life insurance companies being able to discriminate against applicants with any predisposition to disease, whether or not it will manifest, and claim it is “justified” because there is an increased risk. This will likely lead to the outcome above with low overall coverage, specifically to high-risk consumers.

Rather, this narrower policy solution protects the most stakeholders and their interests. Under this solution, federal government could develop a list of specific genes that insurers may screen for and a set of predictive tests for these unpreventable, untreatable genetic disorders, known to cause premature death. For example, in Britain, life insurance companies are allowed to screen for, and deny coverage solely for Huntington’s chorea.131 In the U.S., the gene for
Huntington’s disease could be included on this federally developed list, along with other genes that are known to substantially increase risk of early death, such as TP53 mutations in Li-Fraumeni syndrome, a high-risk, high penetrant gene mutation for breast cancer.\textsuperscript{132} This regulation will be developed federally but implemented by the states.

This policy option allows for the most actuarially just use of genetic information in life insurance. It limits the number of persons denied coverage, while taking into account the life insurance companies’ economic interests, being beneficial for all stakeholders.\textsuperscript{133} Consumers would have more coverage, at actuarially fair prices, and maintain privacy in most of their genetic information. Consumers would also be encouraged to get genetic testing done in order to discover preventable diseases earlier, which would lower costs in the health care industry and keep people alive longer for purposes of life insurance. Finally, life insurance companies would avoid, to an extent, adverse selection, and could maintain economic viability.

D. Conclusion:

For purpose of life insurance, the recommended policy solution is to federally mandate that states and insurance companies only use genetic information to screen for high-risk, high-penetrance genes and variants. A list of these genes and variant will be developed and provided federally and implemented by the states. As noted above, this policy solution is best for all stakeholders. It promotes genetic testing, thus limiting preventable diseases. It increases overall coverage to both high and low risk consumers. Finally, it protects insurance companies’ economic interests by limiting adverse selection. For these reasons, this policy solution is recommended.
III. Insurer Use of Genetic Information in Disability Insurance

In what way do states regulate the use of genetic information by disability insurers, especially when it comes to decisions to grant or deny coverage and decisions about what rate to charge? In what ways, if any, have these regulations been fought in court or enforced? In what ways should these laws be enforced? This section will first provide an overview of what disability insurance is and how insurer use of genetic information might affect insurance companies and policyholders. Next, it will survey current state laws regulating disability insurers’ use of genetic information. Finally, it will combine aspects of these different state regulations into a recommendation for how genetic information should be treated by disability insurers.

A. What is Disability Insurance?

Disability insurance is an insurance product that protects against loss of wages or other income in case of an inability to work. Most of this insurance comes from two sources, Social Security and workmen's compensation. Social Security Disability Insurance (SSDI) covers workers who pay into the Social Security system (most private-sector workers and many public-sector workers) and become totally disabled. Workmen's compensation also functions as a form of disability insurance, and is purchased by employers to protect against liability for on-the-job injuries to employees. In this paper however, references to disability insurance are to private disability insurance. This insurance is often provided to employees as a workplace benefit or purchased by individuals in the private market.

Private disability insurance can be either short-term or long-term. Short-term disability insurance generally pays benefits for periods of three months, six months, or a year, depending on the terms of the policy. Long-term disability insurance pays benefits for anywhere from two
years to ten years, but can also cover policyholders until retirement age or for life, depending on the terms.\textsuperscript{135} Most Americans who have disability insurance receive it through an employer. 38\% of Americans receive short-term disability insurance through an employer, and 31\% of Americans receive long-term coverage through an employer.\textsuperscript{136} When individual policyholders are included, 49\% of Americans have short-term coverage, and 44\% have long-term coverage.\textsuperscript{137}

Disability insurance typically covers losses due to \textit{total disability}—that is, the policyholder may receive benefits so long as he is completely unable to work.\textsuperscript{138} Such a system is easier to administer than a system where individuals are assessed for the extent of their partial disability and paid a commensurate prorated benefit.\textsuperscript{139} Therefore, “disability” and “disabled,” as used in this section, refer to total disability.

B. The Usefulness of Genetic Information for Disability Insurers

Disability insurers are concerned not only by applicants who are currently disabled, but also with applicants who are predisposed to becoming disabled.\textsuperscript{140} For instance, an applicant for disability insurance who exceeds height and weight guidelines will present a high (or even unacceptable) risk to an insurer, even if that person is healthy by all outward appearances. This is because their body mass creates a high probability that they will become disabled in the future, even if they are perfectly healthy and able to work at present.\textsuperscript{141}

Disability insurers’ use of genetic information in issuing policies and setting rates will function similarly to their use of height and weight tables. Genetic information is useful to the extent it is correlated with developing a disability in the future.\textsuperscript{142} For some conditions (the typical example being Huntington's Disease), genetic tests are highly predictive of developing a disease condition in the future that will render a policyholder disabled.\textsuperscript{143} For many conditions, however, the link between a person's genetic profile and their chance of becoming disabled in the
future is only somewhat correlated or unclear with present scientific understanding. Further complications arise because lifestyle choices and environmental influences can interact in complicated ways to ameliorate (or possibly hasten) future development of symptoms caused by genetic mutations.\textsuperscript{144} The risk of future claims might also depend on how a condition predicted by a genetic test will affect a policyholder's ability to work in their chosen occupation. For instance, a bricklayer with a theoretical set of genetic markers correlated with developing osteoporosis would justifiably be considered high risk—there is a high probability that he will be unable to work in his profession in the future because of his condition. The same genetic condition would be less likely to cause a future claim in an IT professional, whose sedentary occupation would probably be unaffected by osteoporosis. Because of these myriad complications, the actuarial usefulness to disability insurers of genetic testing is somewhat limited.\textsuperscript{145} However, this is not true for all genetic conditions, and it will not necessarily remain true in the future, as scientific study on genetic conditions continues moving inexorably forward.

The variable usefulness of genetic information to disability insurers explains, in part, the variable pattern of regulation governing its use. In some instances, genetic information can be freely used by insurers, while in other cases, its use is restricted only for actuarially justified ratemaking.\textsuperscript{146} In many cases, where insurers are not currently considering genetic information, these restrictions are prophylactic—they might become useful in the future when genetic testing is more widespread and the predictive value of tests is higher.

C. State Laws on Disability Insurers' Use of Genetic Information

Individual disability insurance policies are regulated at the state level. Group insurance, including most employer-sponsored disability insurance, is governed largely by federal law.\textsuperscript{147} In total, 19 states have protections from discrimination on the basis of genetic information that
go beyond GINA’s protections for employment and health insurance. Many of these protections extend, in some way, to disability insurance. Because states enact widely-varying statutes to regulate insurance (and consequently, their courts produce widely-varying interpretations of those statutes), it is necessary to assess several state laws to accurately describe how disability insurers may use genetic information.

State regulations of disability insurers’ use of genetic information fall into three general categories: laws that prohibit the use of genetic information by disability insurers, laws that allow the use of genetic information by disability insurers in some way, and laws that require insurers to receive the informed consent of applicants for insurance before requiring those applicants to submit to a genetic test. The following laws are a representative sample of these three categories of regulation.

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<thead>
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<th>Informed consent regimes</th>
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<tbody>
<tr>
<td><strong>California:</strong> Specified list of conditions for which carriers may not be discriminated against. Prohibition applies to underwriting (issuing policies to applicants), ratemaking (the cost to applicants of obtaining insurance), and rebates/discounts. (Cal. Ins. Code § 10143(a))</td>
<td><strong>Arizona:</strong> Discrimination in underwriting and ratemaking permitted against applicants with genetic conditions to the extent the distinction is based on actuarial experience, combined with the medical history of the applicant. (Ariz. Rev. Stat.§ 20-448)</td>
<td><strong>Arizona:</strong> Informed consent required before insurers carry out genetic tests. (Ariz. Rev. Stat § 20-448)</td>
</tr>
<tr>
<td><strong>Colorado:</strong> Complete prohibition on use of genetic information by group disability insurers. Prohibition applies to underwriting and ratemaking. Discrimination is allowed for underwriting and ratemaking for individual disability insurance policies. (Colo. Rev. Stat. § 10-3-1104.7)</td>
<td><strong>Maine:</strong> Discrimination in underwriting is allowed to the extent it is not “unfair,” that is to the extent it is, “reasonably related to anticipated claims experience.” (Me. Rev. Stat. 24-A, § 2159-C)</td>
<td><strong>Colorado:</strong> Informed consent required before carrying out genetic tests on individual disability insurance applicants. (Colo Rev. Stat. § 10-3-1104.7(10)(a))</td>
</tr>
<tr>
<td><strong>Prohibition on use of genetic information by disability insurers</strong></td>
<td><strong>Allowed use of genetic information by disability insurers</strong></td>
<td><strong>Informed consent regimes</strong></td>
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</tr>
<tr>
<td><em>Kansas</em>: Prohibition on genetic discrimination in underwriting. Discrimination in ratemaking allowed to the extent the difference in rate is “reasonably related to the risk involved.” (Kan. Stat. § 40-2259(d))</td>
<td></td>
<td><em>Florida</em>: Prohibition on the release of genetic information by private parties without the informed consent of the DNA donor. Violations are a misdemeanor. Allowance for retesting after a denial based on DNA test. (Fla. Stat. § 760.40)</td>
</tr>
</tbody>
</table>

1. **Prohibition on use in underwriting and eligibility**

The strongest restriction on disability insurers' use of genetic information are those laws that prohibit insurers from considering genetic information when making underwriting decisions or determining eligibility for coverage. Disability insurers in these states must issue coverage without regard to genetic information, although the definition of “information” varies from state to state. The following is a non-exhaustive description of the law in these regimes.

**California:**

The Golden State stands unique for the manner in which it controls disability insurers’ use of genetic information. The California Insurance Code prohibits discrimination in underwriting or policy renewal “solely by reason of the fact that the person to be insured carries a gene which may, under some circumstances, be associated with disability in that person's offspring, but which causes no adverse effects on the carrier.” The Insurance Code specifies examples of these conditions, including “Tay-Sachs trait, sickle cell trait, thalassemia trait, and X-linked hemophilia A.” This means that disability insurers may not discriminate against insurance customers who only carry disease-causing genetic traits but do not themselves express the trait. The same provision in the Insurance Code also prohibits any rebate or discount based
on one’s status as a carrier of a genetic condition. Discrimination in ratemaking based on one’s carrier status is also prohibited in California.

This section of the Insurance Code has never been the subject of a court case or an administrative action—the law remains more of an academic curiosity, rather than a point of legal contention. For instance, it has never been contested or decided by a court whether a trait must be a discrete diagnosable condition, or simply a genetic marker or series of markers that raise the risk of one’s children developing a disease, to qualify for protection under the law.

**Colorado:**

Colorado law has blanket prohibition on the use of genetic test results in providing group disability insurance. This statute applies specifically to information received from genetic testing, which the statute defines as a laboratory test of genomic material used to detect disease or illness. Whether, or to what extent, this would prohibit insurer use of genetic information acquired by some means other than laboratory ‘testing’ has not been decided by a court or agency in Colorado.

Individual disability insurance plans are not covered by Colorado’s genetic nondiscrimination law—the statute states specifically that the intent is to “prevent information derived from genetic testing from being used to deny access to group disability insurance . . .” By implication, the results of genetic testing may be used in making underwriting and rate decisions for individual disability insurance plans. However, insurers selling individual disability insurance policies must still receive informed consent from consumers before carrying out this testing.
Kansas:

The law of Kansas operates somewhat differently than its neighbor Colorado. In Kansas, disability insurers are not forbidden by statute from receiving the results of genetic tests from policy applicants. However, even if disability insurers do possess genetic test information about those applicants, they may not use the test results to deny coverage.\textsuperscript{159} Disability insurers in Kansas are permitted by statute to consider genetic test results when setting rates, provided that the rates they set based on genetic test results are “reasonably related to the risk involved.”\textsuperscript{160} This means that disability insurers in Kansas must offer policies for sale to all customers, regardless of any genetic conditions those customers may have. However, insurers may charge customers more for their policies if their genetic test results signal a high risk of the customer becoming disabled in the future.

Like Colorado, there have been no judicial or administrative decisions that interpret or clarify this statute; in particular, no decision has been rendered on what does or does not constitute a reasonable relationship between risk and insurance rate.

2. Allowable use in underwriting and eligibility\textsuperscript{161}

Some states allow disability insurers to consider consumers’ genetic information when deciding whether to issue coverage and what rate to charge. The manner and extent of this allowable use varies by jurisdiction, and the following examples from Arizona and Maine are illustrative of trends in these statutes.

Arizona:

The law of Arizona allows more leeway than either Colorado or Kansas for insurers who consider genetic conditions in issuing policies and setting rates. Disability insurers in Arizona are prohibited from rejecting applications or setting rates and conditions based on genetic
conditions, except when the applicant's medical history, coupled with actuarial projections, establishes that 'substantial differences in claims' are likely to result from the condition. Any decision to deny coverage or apply differential rates must also be based on the “diagnosis of the condition related to information obtained as a result of a genetic test.” The statute further defines 'genetic test' as an analysis of DNA or gene products for a propensity of susceptibility to disease or illness, damage due to environmental factors, or carrier status. Therefore, Arizona law allows consideration of genetic tests in ratemaking and policy issuance if the tests reveal a diagnosis of a condition, but not to consider factors like propensity to develop conditions in the future or carrier status. Failing to act in accord with this statutory provision is defined by the statute as unfair discrimination.

Maine:

Maine law prohibits "unfair discrimination" in the use of genetic information for issuing, extending, or renewing a disability insurance policy. Unfair discrimination, defined by the same statute, includes “but is not limited to[] the application of the results of a genetic test in a manner that is not reasonably related to anticipated claims experience.” In this way, Maine law allows the use of genetic information for underwriting decisions so long as the discrimination is not unfair; that is, so long as the discriminatory decision is related to anticipated claims and not a statistically unrelated factor.

Maine law specifically allows the Maine Bureau of Insurance Superintendent to initiate proceedings on finding credible allegations of unfair discrimination. The Superintendent may also issue injunctions and fines as necessary for enforcement of the statute. Insurer requests for genetic tests must also be accompanied with informed consent of the insurance applicant, and
the results of the test must be disclosed to the applicant if requested.\textsuperscript{167} No published judicial or administrative decision has yet invoked the statute in regard to disability insurance.

3. \textbf{Informed consent statutes}

The most common form of regulation on the use of genetic information in the disability insurance market are statutes that require insurers to receive informed consent from consumers before conducting genetic tests.\textsuperscript{168} These regulations are not, per se, restrictions on the ability of insurers to use genetic information in making underwriting or ratemaking decisions. In some states, insurers must receive informed consent (or authorization) from consumers before subjecting those customers to genetic testing, although many states allow insurers to use genetic information they do receive from authorized tests in making underwriting or rate setting determinations. For instance, Arizona requires consumer authorization before a genetic test can be carried out for a disability insurer, although disability insurers may use the results of genetic tests to make coverage determinations.\textsuperscript{169} Colorado also requires informed consent of individuals before conducting genetic testing, but this provision applies exclusively to \textit{individual} disability insurance plans (as noted previously, group disability insurers in Colorado are prohibited from using genetic information of applicants in making coverage decisions).\textsuperscript{170} The Colorado Insurance Commissioner has produced a model form used for obtaining consent for a genetic test by individual disability insurers.\textsuperscript{171}

One variation on the informed consent doctrine comes from Florida, which does not prohibit genetic testing by disability insurers but requires informed consent from individuals being tested.\textsuperscript{172} Florida’s civil rights code prohibits the release of genetic information to third parties without informed consent, and punishes unauthorized disclosure as a misdemeanor.\textsuperscript{173} Insurers must also notify insurance applicants if the results of genetic tests cause the insurer to
deny coverage to the applicant. Florida law goes a step further still, allowing that, if an adverse genetic test result causes an application for insurance to be rejected, the applicant has a right to be re-tested to verify the accuracy of the test.

D. Policy suggestions for the use of genetic information by disability insurers

Deciding the best approach for regulating disability insurers’ use of genetic information requires, first, a careful contemplation of the purpose served and unique properties of disability insurance. Private disability insurance is a product unlike life insurance, in that it provides income to meet a worker’s needs while they are still alive—a time when their basic needs must still be sustained. In this way, strict actuarial projections leading to high levels of coverage denial (or prohibitively expensive coverage) will leave a large group of people uninsured and unemployable. At the same time, the pool of people purchasing disability insurance policies is smaller than health insurance—especially individual policies. The market is thus more prone to adverse selection and less able to spread risk across a wide group of policyholders. Therefore, complete prohibitions on the use of genetic information will take a valuable actuarial tool out of the hands of insurers and result in higher rates for all policyholders.

The solution, therefore, requires a balance between the needs of consumers to access coverage, and the needs of insurers to have a balanced risk pool and ample data on which to draw. The key first step for regulators in striking this balance is to define conduct in which insurers may not engage—unfair discrimination. When it comes to the use of genetic information in disability insurance, the state of Maine offers an attractive definition. Unfair discrimination is defined in Maine as action including, but not limited to, “the application of the results of a genetic test in a manner that is not reasonably related to anticipated claims experience.” Disability insurers may make coverage decisions based on genetic information...
so long as they are not engaging in unfair discrimination. The phrase “reasonably related to anticipated claims experience” can be refined further by looking to the law of Arizona. The Grand Canyon State requires that discriminatory coverage decisions be based on genetic testing, considering an applicant’s individual medical history and actuarial projections.\textsuperscript{180} Put together, these factors will allow disability insurers to consider genetic information in a manner based only on laboratory-conducted genetic tests, considering both objective risk (actuarial projections) and subjective analysis (individual medical histories). This approach allows insurers to consider important actuarial risks, while forcing them to justify denials based on sound evidence and individualized risk profiles.

Once insurers are free to use genetic information in making coverage decisions, the analysis must next turn to extent to which that information may be used. The question is again one of balancing the need of access with the necessity of actuarially-sound projections by insurers. Given the importance of disability insurance to wide swaths of the working population, the right to access should properly predominate, so that workers have the opportunity to hedge against future disabilities despite genetic predispositions.\textsuperscript{181} Therefore, an approach similar to Kansas’ is ideal. Disability insurers in the Sunflower State may not use the results of genetic testing to deny disability insurance coverage, but they may use those results to set rates, provided that those rates are based on sound actuarial principles.\textsuperscript{182} Coverage, in this way, is always theoretically accessible to consumers.

The fact remains that access is of limited use if rates are prohibitively expensive for consumers. Purchasers of individual disability plans are especially vulnerable, because they must foot the entire cost without assistance from an employer. Solutions to this problem are ultimately beyond the scope of this paper and will involve legislative action such as subsidies for
disability insurance or universal disability coverage. States can, however, take steps to limit the number of people who might be priced out of the market. States should limit permitted price discrimination to conditions that can be diagnosed directly from a genetic test (a genetically-linked disease), as opposed to letting insurers adjust rates based on a propensity towards future diseases based on having some mutations. In the former case, the link is clear enough to establish clear, judicially-testable standards for determining whether discrimination is fair. In the latter case, the links are likely to be too attenuated or full of uncertainty to justify discrimination, and will ensnare far more applicants. A downside to this approach is that it does not account for future scientific advances that will improve the predictive value of genetic testing for the development of medical conditions in the future. These advances should be accounted for via the administrative state, which can more easily and flexibly promulgate rules for conditions that may considered in setting rates.

Finally, any genetic test ordered by an insurer should only be conducted with the informed consent of test subjects. Florida’s statutory requirement of informed consent offers strong protection for genetic information. It declares that DNA is the property of the person from which it is drawn and that private entities may not release the information without the informed consent of the donor, and makes violations of the act a misdemeanor. Further, it allows for re-testing if an adverse consequence (such as denial of insurance) results from the test. A well-worded example of a model informed consent form was produced by the Colorado Insurance Commissioner. Among other things, the form tells the insurance applicant the nature of the DNA test, the purpose of conducting test, and that the test is not compulsory under the law. It is true that applicants who decline to undergo genetic testing may be denied insurance altogether on account of their refusal. However, informed consent at least allows
individuals to make a rational and fully-informed decision, weighing the costs and benefits, before choosing to submit to or decline a genetic test. Misunderstandings and consequent litigation are also less likely when all involved parties are fully informed of their rights.

E. The future of using genetic information for disability insurance

Much of the regulation of disability insurers’ use of genetic information currently in place is proactive—it anticipates future legal conflict, but this conflict has thus far not materialized. The fact that there are currently few litigated cases involving disability insurers’ use of genetic information does not portend similar quiet in the future, for the predictive power of genetics continues to expand.\(^{189}\) Synthesizing the best aspects of current law will help ensure access for customers and solvency for insurers. The solutions presented here combine guaranteed underwriting, fair pricing, and informed consent in order to balance the needs of all concerned parties.

IV. Insurer Use of Genetic Information in Long-Term Care (LTC) Insurance

Despite its similarities to life and disability insurance, long-term care (LTC) insurance faces its own unique challenges regarding insurer use of genetic information and unfair discrimination. The LTC market is significantly different from life or disability insurance and requires separate examination and policy recommendations to address its specific needs. Part I of this section describes long-term care insurance; Part II discusses the growing need for LTC in the United States; Part III surveys different state statutory approaches to LTC insurer use of genetic information; Part IV explores potential policy solutions; Part V recommends which policy option to implement; and Part VI concludes.
A. What is Long-Term Care Insurance?

LTC is a product designed to cover the costs of extended care due to disability or extended illness. However, LTC is distinct from disability insurance. Disability insurance is designed to replace income payments when the insured can no longer work after becoming disabled. By contrast, LTC can cover a wide range of care needs from home health, to skilled nursing, to help with daily activities. LTC does not aim to protect against the costs of medical improvement, but instead aims to cover costs associated with maintaining care for life “as you are.” LTC policies are available from different sources, including the individual market, employers, and association policies.

Long-term care is paid for by a variety of payers, including Medicare and Medicaid, private group insurance, and private individuals. Medicare and Medicaid pay for care directly, whereas private insurance companies charge individual policy holders premiums and then payout the individuals’ submitted claims. Others rely on family members to provide their care free of charge, and therefore do not participate in LTC markets.

The federal government plays the largest role in funding long-term care through Medicare and Medicaid. Medicaid pays for over half of all the long-term care in the United States. But Medicaid coverage only covers low income individuals, and thus most Americans cannot rely on the program to cover their LTC expenses. Medicare coverage is even more limited. Given these gaps, the LTC market relies on private insurance policies to cover to those who do not fall under the either of the federal programs. These private payers are regulated at the state level. Thus, even though the federal government is the largest payer for long term care, this paper focuses on the state regulation aspects of the private LTC market.
In considering who purchases private LTC coverage, research shows that usually risk adverse people strongly prefer insuring against the risks of acquiring a long-term care financial burden.\textsuperscript{201} Brown and Finkelstein explain that the United States private long-term care insurance market lacks development, noting that only four percent of long-term care expense are paid for by private insurance policies, and nearly one-third of the same expenses are paid for out of pocket.\textsuperscript{202} Even the market that does exist is struggling.\textsuperscript{203} Individuals rely on the private market to help alleviate some of the pressures associated with older age, but insurers frequently struggle to accurately price plans due to the complex nature of measuring long-term risk, which drastically increases premiums, and in turn causes fewer people to purchase the coverage they need.\textsuperscript{204} In 2014, only 7.4 million had private LTC coverage, and as many as one-third of policies issued end up lapsing.\textsuperscript{205}

**B. Growing Need for Long-Term Care Insurance in the United States**

The growing elderly population in the United States amplifies the need to address the serious issues facing the LTC insurance market. It is no secret that Americans now live longer than ever before. But this extended life-span comes with significant cost. People living longer means that the costs of diseases and disabilities will increase, creating a large economic burden.\textsuperscript{206} Even though elderly citizens on Medicare may not need to worry as much about health insurance expenses, at least one commentator has called LTC “one of the largest financial risks in the history of [the Baby Boomer] generation.”\textsuperscript{207} NAIC suggests that buying LTC is important for individuals who wish to avoid using their personal assets for long-term care, and also for individuals who wish to avoid relying on governmental aid or family members.\textsuperscript{208}

Despite the growing age of the population, estimates predict that two-thirds of the elderly population will not enter a nursing home.\textsuperscript{209} Of the third who does enter, their stay in nursing
facilities is expected to last less than one year. Yet, 12 percent of men and 22 percent of women stay beyond three years, and at a projected cost of $50,000 per year, these expenses add up quickly. A more recent study suggests that nearly half of all Americans turning 65 between 2015 and 2019 will need long term care. Despite the potential risks, some commentators suggest that not purchasing long-term care insurance is a justifiable choice because the expected benefit of purchasing coverage is less than simply not having LTC coverage. Others note that some consumers view Medicaid, out-of-pocket payment, or relying on family members to provide coverage as substitutes in lieu of purchasing LTC insurance. Notwithstanding these views, this paper progresses assuming that purchasing long-term care insurance is the modern LTC consumers’ best interests given the continued increase in LTC costs. The recent statistics demonstrate the need for adequate protection and access to the long-term care market. LTC is a unique market and industry, demanding a unique and independent solution. In other words, the suggestions made within this paper related to life or disability insurance may not work as well in LTC given the conditions of the LTC market.

Genetic information could be useful to long term care insurers in the underwriting process, or in determining whether to issue a policy at all. It can also be useful to consumers concerned about future health risks. But such use by either constituency comes with advantages and disadvantages. For example, consider Alzheimer’s Disease. Testing the APOE gene can indicate an individual’s risk of developing the disease. Learning that one has markers that indicate a higher risk of developing Alzheimer’s may lead individuals to adversely select (or use their superior information about their risk) and buy a LTC policy to cover expenses that they know they will likely incur as a result of the disease. It can be useful to insurers to set accurate rates with actuarially fair justification, which may help to shore up the unsteady LTC market,
and may also allow for better risk pooling. However, it could create large distrust in the industry, incentivizing fewer people to get tested to know their chance at having a harmful disease, and simultaneously driving them away from the LTC market. States’ responses to whether LTC insurers may use genetic information lie on a spectrum ranging from completely barring insurer use to allowing use if the policy is actuarially justified.

C. State Regulation of Long-Term Care Insurance

1. Overview of state level regulation of LTC insurer use of genetic information

While GINA is the main federal law governing genetic insurer use of genetic information, its provisions do not extend to LTC insurance. Long-term care insurance, in accord with most other insurance lines, is therefore regulated at the state level. Although 19 states have enacted protections for individuals’ genetic information beyond GINA, not all of these apply to LTC insurance. The following table presents an overview of the statutory approaches of various state approaches to regulating LTC insurer use of genetic information. This table is meant to provide context for the overall landscape of LTC genetic information regulation. The table includes the 19 states noted above as representative examples. However, this paper includes discussion of other state statutes not included in the table. In addition, many states have not addressed the question.

<table>
<thead>
<tr>
<th>States Prohibiting LTC Insurer Use of Genetic Information</th>
<th>States Allowing Insurer Use if Actuarially Justified</th>
<th>States where LTC insurer use of genetic information is not regulated</th>
</tr>
</thead>
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<tr>
<td>Colorado: LTC insurers may not use the information for any “nontherapeutic purpose” or underwriting. COLO. REV. STAT. ANN. § 10-3-1104.7(3).</td>
<td>Maine: LTC insurers may not use genetic information to unfairly discriminate unless it is “reasonably related to anticipated claims experience.” ME. STAT. ANN. tit. 24-A § 2159-C(3).</td>
<td>Arizona: LTC insurance is not covered by the restrictions on insurer use of genetic information. ARIZ. REV. STAT. ANN. § 20-448(E).</td>
</tr>
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<tr>
<td><strong>Kansas</strong>: LTC insurer may not require a genetic test, nor use any genetic information in underwriting for LTC. [KAN. STAT. ANN. § 40-2259(d)(1)].</td>
<td><strong>Maryland</strong>: Genetic test results may be used only if it is actuarially justified, including the denial or limitation of coverage as well as ratemaking. [MD. CODE. ANN. INS. § 18-120(c)].</td>
<td><strong>California</strong>: LTC insurance not covered by provision barring genetic information as a basis for insurance application decisions. [CAL. INS. CODE § 10140(b)]. LTC is also not covered by underwriting protections. [CAL. INS. CODE §10146].</td>
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<td><strong>Oregon</strong>: LTC insurers may not use genetic information in the process of issuing or setting a policy without the express authorization of the individual applicant. [OR. STAT. REV. STAT. ANN. § 746.135].</td>
<td><strong>Massachusetts</strong>: May not use genetic information without actuarial justification, anticipated claim experience or “reliable information related to the insured’s mortality or morbidity.” [MASS. GEN. LAWS ANN. ch. 175 § 108(b)].</td>
<td><strong>Idaho</strong>: LTC insurers are not covered by the ban on using genetic information for unfair discrimination. [IDAHO CODE § 41-1313].</td>
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<td><strong>Wisconsin</strong>: No aspect of LTC insurance coverage may be based on requiring an insured to obtain a genetic test, or the results of any genetic test. [WISC. STAT. ANN. § 631.89(2)(d)].</td>
<td><strong>New Mexico</strong>: LTC insurers may use genetic information in underwriting or to discriminate if actuarially justified. [N.M. STAT. ANN. §§ 24-21-3(D), 24-21-4(c)].</td>
<td><strong>Kentucky</strong>: LTC not included in prohibition of insurers’ requiring a genetic test before issuing a policy. [KENT. REV. STAT. ANN. § 304.12-085(3)].</td>
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<tr>
<td><strong>Vermont</strong>: LTC insurer’s may not require an individual to obtain a genetic test to get coverage. [VT. STAT. ANN. tit. 18 § 9334(a)]. LTC insurers may use genetic information only where there is a relationship between the information and the insurance risk based on “actual or reasonably anticipated experience.” [VT. STAT. ANN. tit. 8 § 4724(7)(D)].</td>
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<td><strong>Minnesota</strong>: Restrictions on use of genetic tests does not apply to LTC insurers. [MINN. STAT. ANN. § 72A.139].</td>
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<tr>
<td>Missouri: LTC is expressly excluded from the restrictions on using genetic information. Mo. Ann. Stat. § 375.1303(3).</td>
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<td>New York: LTC insurers may use genetic tests for adverse underwriting decisions but must notify the insured the genetic test is the basis for such decision. N.Y. Ins. Law § 2615(e).</td>
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2. States that prohibit LTC insurer use of genetic information

Although there are potential benefits to allowing LTC insurers to use genetic information, some states ban LTC insurers from using genetic information. As shown in the table, four
states—Colorado, Kansas, Oregon, and Wisconsin—regulate this way. However, not all bans apply across the board. Kansas, for example, only partially bans use.

When determining how to regulate insurer use of genetic information, the Colorado General Assembly recognized the modern advances in genetics and genetic technologies that have led to better diagnoses, treatments and scientific knowledge about disease. Colorado recognizes genetic information as “the unique property of the individual,” which, if discovered by third parties (including insurance companies), could yield adverse consequences to the individual. This privacy concern informs Colorado’s approach to LTC insurers use of genetic information. Under Colorado law, any release of an insured’s genetic information for a “nontherapeutic purpose” requires written informed consent of the insured. Additionally, Colorado takes a strong stance against insurer use of genetic information. LTC insurers are expressly banned from using genetic information for any underwriting purposes. This means that even though an LTC insurer in Colorado may be able to actuarially justify using the information, such use is forbidden. If the state insurance commissioner finds that a Colorado LTC insurer committed a violation of the law, she may issue a cease and desist order to the offending company and order a monetary fine of up to $3,000 per offense, revoke the insurer’s license, or payout an insured’s claim.

In Kansas, LTC insurers also face partial bans on their use of genetic information. Kansas bars LTC insurers from using an individuals or an individual’s family member’s genetic information in writing a policy. But Kansas LTC insurers may ask about genetic tests when deciding to issue a policy. The Kansas statute creates a small exception, which allows limited use in ratemaking where the genetic information is “reasonably related to the risk” being insured.
Oregon takes a different approach. Under its code, if an insurer asks someone to take a genetic test as a part of an application for insurance, the insurer is obligated to reveal the results to the applicant, and must receive special permission from the applicant to then use those results.\textsuperscript{228} Regardless of whether permission is granted, the applicant’s test results cannot be used to “affect any policy for hospital or medical expenses.”\textsuperscript{229} The meaning of this phrase has not been litigated, but LTC could reasonably fall under its scope. Assuming LTC falls under the statute, the language operates as a ban on insurer use of the applicant’s own genetic information to adversely affect an LTC policy. LTC insurer use of a blood relative’s genetic information in relation to an insured’s policy is expressly banned.\textsuperscript{230}

Wisconsin insurers cannot require or force an insured to get a genetic test, or to reveal results of the tests.\textsuperscript{231} Insurers also cannot base decisions on family member tests.\textsuperscript{232} Similar prohibitions are in place when determining rates or “any other aspects of insurance coverage.”\textsuperscript{233} While Wisconsin does not expressly name long-term care insurance as a protected industry, the industry falls under the statute’s broad language banning genetic information use by an insurer generally. This is supported by the fact that the statute carves out an expressly exception for life insurance and income continuation coverage only.\textsuperscript{234}

3. States that allow LTC insurers to use genetic information if actuarially justified

Other states regulate insurer use of genetic information by requiring an insurer to demonstrate that such use is actuarially justified. Other states disallow unfair discrimination without a sufficient reason. While in lay terms “unfair” connotes ideas of justice, morality, and having an even chance, in the insurance industry, unfair discrimination refers to a practice by an insurer that is not actuarially justified.\textsuperscript{235} As has been amply discussed previously in this paper, actuarial justification is difficult to define. Even in the insurance industry a precise or uniform
definition of the term is difficult to discern. Because we lack a uniform definition, the term could create different standards in different jurisdictions.

In Maine, for example, long term care insurers ordinarily may not use genetic information for determinations related to a long term care policy. Insurers who use genetic information in any way “not reasonably related to anticipated claims experience,” commit unfair discrimination. In other words, so long as the insurer shows that using genetic information is related to anticipated claims experience, the use is permitted. Penalties for violations include an order from the state commissioner to cease and desist, and can include monetary penalties. The statute further requires that if an insurer plans to use the results of a genetic test in accordance with the statute, the company must to notify the insured of the need for such a test, and obtain written confirmation of the insured’s desire to know or not know the results of their test.

Maryland’s LTC insurers are subject to comparable restrictions. Normally, insurers in the state are forbidden from asking for or requiring a genetic test in issuing a policy or ratemaking. Insurers likewise may not typically use genetic information they may receive in making policy or ratemaking decisions. But, “if the use is based on sound actuarial principles,” an insurer may in fact use genetic information in setting the rate and determining the conditions of the policy. The Maryland act does not lay out any penalties for violating the law.

Massachusetts also forbids an insurer from using genetic testing in unfair discrimination, and from requiring applicants to obtain a “genetic test.” But Massachusetts has a limited definition of what constitutes a genetic test for the purpose of long-term care insurance, expressly excluding “any test for the purpose of diagnosing or detecting and existing disease process; any test performed due to the presence of symptoms, signs, or other manifestations of a
Companies may not unfairly discriminate on the basis of a genetic test. However, companies may still ask applicants if they have taken a genetic test, though applicants are not required to answer it. If an applicant does give the information, the insurance company may use it for the policy “provided that such information is reliable information relating to the insured’s mortality or morbidity, based on sound actuarial principles, or actual or reasonably anticipated experience.” If the company is found to be using the information inappropriately it may be ordered to cease and desist the commissioner and pay a monetary penalty. This research has not yielded an example of such an order.

New Mexico’s approach is slightly different. LTC insurers in New Mexico are exempt from restrictions on the use of genetic information so long as the use “is based on sound actuarial principles or related to actual or reasonable related experience.” But, insurers must give written notice to the individual before or at the time of the genetic test that the results may be broadly used for long-term care business decisions. Vermont’s approach is similar to that of Massachusetts and Maryland. Vermont bans insurers from requiring a genetic test. Using genetic tests is usually an unfair insurance practice. Genetic testing information constitutes unfair discrimination based on medical information except “where there is not a relationship between the medical information and the cost of the insurance risk that the insurer would assume by insuring the proposed insured.” Medical information includes the results of genetic tests. This approach allows the insurer to use “actual or reasonably anticipated experience” to establish such a relationship.
4. **States that allow LTC insurers the use of genetic information in the market**

Many of the states have not addressed insurer use of genetic information. Because GINA does not cover long-term care insurance, where a state has not addressed whether an insurer may use genetic information insurers in that state are allowed unrestricted use of the information.

Peculiarly, several of the states that do regulate the use of genetic information in life and disability insurance, do not do regulate its use in LTC. Because of this, many states allow unrestricted use by omission. This means that even though they have regulations on insurer use of genetic information that apply to other lines of insurance, because LTC is not included in the language of the statutes, the regulations do not apply to LTC insurers. It is unclear in many of these states if omitting LTC was intention or the result of oversight.

For example, Arizona has prohibited the use of genetic information for unfair discrimination in life and disability insurance, but not long-term care insurance. California likewise only disallows genetic information for applications in disability insurance, and therefore allows it in long-term care markets. California also excludes LTC from underwriting protections. Other states that exclude LTC insurers from genetic information regulations are: Idaho, Kentucky, Minnesota, and New Jersey.

Similarly, Florida adopted provisions akin to those of GINA, only prohibiting using genetic information in health insurance, and expressly does not apply the prohibition to long-term care insurance. Many states have enacted provisions adopting the approach of GINA, and expressly excluding long-term care insurance from the prohibition. Other states expressly exclude LTC insurers from genetic regulations, too. Montana bans insurers broadly from using genetic information, but nonetheless excluding long-term insurance. Texas and Missouri likewise expressly ban LTC insurers from regulations.
Still other states employ more unique approaches. South Carolina, though lacking express statutory language on genetic information, provides “[a] long term care insurance policy may not . . . be canceled, nonrenewed, or otherwise terminated except for nonpayment of the premium.” Therefore this scheme seems to protect a policy holder that discovers a genetic condition after obtaining coverage, depending on the terms of the policy. The statute, while preventing termination of an existing policy based on discovery of a genetic condition or a genetic test, says nothing about a company’s ability to use it in the underwriting or ratemaking processes. So, this protection may be ineffective in helping insureds keep their policies if companies raise rates above an actuarially fair price level. New York falls into this category because although its insurers cannot require tests without informed consent, once an applicant gives consent the insurer is free to use the information for “adverse underwriting decisions” regardless of any actuarial justification. Meanwhile, New Hampshire expresses allows unrestricted use of genetic information by its LTC insurers, but they may only use it in relation to the LTC specific coverage. In other words, New Hampshire insurers doing business across multiple lines of insurance can use genetic information for LTC insurance, but not, for example, housing insurance.

5. Litigating Statutes

Litigation of these statutes meanings, and their applicability to the LTC are rare to nonexistent. Legal research seeking to find example cases proves to be unavailing. For the purposes of this section of the paper, I employed the legal search engine Westlaw to try and find cases where language in a statute has been litigated and defined by a court. There are often phrases, such as the one discussed above related to the Oregon statute that may need judicial clarification where the legislature has left the term vague. Yet as of this final draft, there has been no direct
challenge to the Oregon law. On Westlaw, a researcher can track the sources in which the statute has been cited to see cases or other secondary source materials where the statute is discussed at length. However, most of the state statutes discussed in this paper are not litigated relevant to their meaning or application to LTC. The Oregon statute, for instance, has been cited by only one court opinion, but the case was entirely unrelated to application or meaning of the terms to the statute to LTC. Instead it was about the applicability of DNA to a criminal case.²⁷¹ The statute has not been cited in any other case, and the criminal case was decided over two decades ago. This is not uncommon across the other states highlighted herein.

The lack of litigation of these statutes across the country has a variety of effects on the LTC market. For instance, a lack of challenge to the statutes may indicate that many insurance companies are simply unaware of them and their applicability to their business in the state. Applicants and insured may also be unaware of the statutes. This is understandable given that companies doing business across multiple jurisdictions may be unaware of change in laws or how the state regulations are unique to specified jurisdictions. But this seems unlikely.

A more plausible explanation is that LTC insurers do not wish to challenge the laws or instead comply with them voluntarily. This explanation makes sense because while there are not cases showing insurers challenging the applicability of the laws to their business practices, there likewise are not cases where insureds are challenging that insurers have violated the law. Leaving the language of the statutes unchanged maintains the status quo. This points to a balance of compliance on the side of insurers and acceptance of insurance practices by the insureds.

Still another explanation may be that current practice in the LTC industry seems to be that genetic information is not heavily used or relied upon. In using information, LTC companies risk moral pushback, even if they could legally use the information under state law. The cost
associated with obtaining and maintaining genetic information over the long time period of an LTC policy may be too burdensome on insurer’s financial health.\textsuperscript{272} This cost, combined with high litigation costs, may create too strong a disincentive for companies to litigate the precise reach of these statutes. Costs can likewise be a barrier for insureds or applicants, who may simply pursue coverage from an alternate company rather than turn to litigation upon denial of an application.

D. Policy Options for insurer use of genetic information in Long-Term Care Insurance

Effective policy solutions to address LTC insurer use of genetic information require careful consideration of the state of the LTC market, the insurance industry, and the interests of those seeking (or abstaining from) coverage. Given the unique situation of the LTC market, it is imperative that a policy solution consider both the use of genetic information as well as the greater needs of the LTC market as a whole. The work of Allaire, Brown, and Weiner is instructive when looking at attitude and preferences of insureds, and can help inform policy solutions to help the industry forward.\textsuperscript{273} Several factors need to be considered from the perspective of the insured, including trust between insureds and the private market,\textsuperscript{274} cost,\textsuperscript{275} and attitudes about the role of government in providing long-term care,\textsuperscript{276} and how these could be impacted by a policy on the insurer’s use of genetic information. From the perspective of the LTC insurer, it is important to consider transaction costs, adverse selection, and risks associated with long-term contracting.\textsuperscript{277} With these collective interests in mind, this paper proceeds by offering several policy options, and making an ultimate recommendation.

1. Allow LTC Insurers Complete Use of Genetic Information, Regardless of Justification

One possible policy approach is to allow insurers in the LTC market complete and unregulated use of genetic information. This approach stops short of requiring or compelling
insureds to have a genetic test to get insurance coverage. However, the approach would allow LTC insurers to ask about genetic information, and to use it if an applicant has been tested. It also allows LTC insurers to use genetic information if they learn that an insured obtained a test following issuance of a policy.

Assessment of the effects of such a policy requires looking at outcomes from a variety of perspectives. From the perspective of the insured, this may be viewed as too far an intrusion into the personal health information needed to compute a rate for long-term care. It may also foster a strong disincentive for individuals to ever receive a genetic test, even though such tests may reveal valuable information about future devastating diseases such as differing cancers, Alzheimer’s, or Huntington’s Disease. Such concerns are likely to be echoed by genetic counselors. But insurers, assuming they could develop accurate underwriting policies, might be able to use the information to better set rates for the policies that they are offering. With more accurate information, costs could be contained by actuarially pricing premiums in a way that could shore up one of the main reasons the LTC market is currently so fragile. More insurers may also be more likely to enter the market if they know that they can maximize information.

2. **Completely Bar Insurer Use of Genetic Information**

On the opposite end of the spectrum, an alternative policy option is to completely bar the use of genetic information by LTC insurers. This would mean that even if an insurer knows that an insured has taken a genetic test, and even if the insurer has a copy of those results, the insurer would be prohibited from using those results at any point in the insurance process. This means that even knowing that someone presents a higher risk and should be priced higher, insurers would be unable to set a price based solely off of an applicant’s genetic information.
This, of course, would result in essentially the opposite policy effects as allowing the uninhibited use suggested in Policy A. Insureds would have no LTC barrier or consequence imposed for having a genetic test. In addition, genetic counselors could confidently advise their clients that for LTC, the need not obtain an insurance policy prior getting tested for potentially life altering diseases. This could also help to alleviate concerns about trust between insureds and the private insurance market. This may also create a more equitable LTC market given that racial minorities are more likely to belief genetic information will be misused. But this means that insurers will be unable to take into account crucial information that may force them to choose not to issue a policy to someone they otherwise would if the information could be used to price the rates accurately. This may also lead to insurers refusing to join the market, or incentivize those in it to withdraw.

3. **Allow Insurer Use of Genetic Information only when Actuarially Justified**

One reconciliation of the problem presented by the two of extremes of Policy A and Policy B is to allow insurers the ability to use genetic information when it is actuarially justified. This would mean that if an insurer can justify discriminating against an insured or raising their premium for actuarial reasons, then it should be allowed to do so. This approach is comparable the approach already adopted in the states requiring actuarial justification. This means that for diseases with genetic predispositions effecting long-term care needs, such as Alzheimer’s, genetic information could be used by an insurer to set a higher rate for that patient over someone who has not tested positive for such a disease.

This scenario, unsurprisingly, also has varied effects. On the one hand, it allows insurers and insureds alike to know what to expect after a genetic test is performed. The insurer knows she will be able to request it, and then use the information if it can be actuarially justified.
Likewise, the insured knows she may be charged a premium for LTC that is higher if she tests positive. And insurers know that insureds can get tested without results being used “against” them if it cannot be justified. This measure should significantly improve the overall integrity of policies being issued, since it can help to alleviate adverse selection and allow insurance companies to more accurately price plans.

However, such a system may undermine lay notions of fairness and just outcomes. Insureds may be skeptical of a market that uses someone’s genetic condition, a characteristic outside of the individual’s control against him or her.282 Similarly, the actuarially justified premium may be too high for insureds to afford, so they may choose not to enter the market at all. If these individuals are priced out of coverage, it may mean that allowing actuarial justification is in fact unjustified when considering the broad LTC market as a whole. One other reasonably foreseeable outcome is that some conditions could slip through the cracks. That is, a genetic condition may be so rare that there is not enough data or information known about the condition to actuarially justify charging a different premium than a more commonly understood genetic condition. This, at least hypothetically may create a scenario in which someone who suffers from a rarer disease benefits from lower priced coverage than someone with a justifiable disease simply because there is an information deficit.

4. **Develop an Education Partnership to Increase Public and Professional Knowledge About the Implications of LTC Insurers Use of Genetic Information**

One explanation for the low market participation in LTC insurance is that many individuals “erroneously believe that they already have LTC coverage.”283 Over half of adults think that Medicare covers extended nursing home stays, when in fact it does not.284 The lack of accurate understanding of coverage and the unique features of LTC suggest the need for a policy
solution focused on educating stakeholders about the market, the impact genetic information may have for different stakeholders, and how to navigate the various state insurance schemes.

Education is important in the LTC market, because both education and LTC care decisions are forward looking. Additionally, research demonstrates that individuals’ knowledge about LTC is positively and significantly predictive of if they will purchase a plan. Furthermore, consumers are less willing to buy LTC insurance if they are uninformed about the underlying risks it is designed to protect. In one study, as many as twenty nine percent of participants indicated a desire to purchase LTC care after receiving additional information about risks associated with LTC expenses.

Addressing insurer use of genetic information and increasing knowledge of LTC are not mutually exclusive. Instead, it may be useful and efficient to incorporate both into a one policy to address the dual concerns with our overall LTC policy suggestions (genetic use and LTC participation). This policy requires the collaboration of a several stakeholders: insurers, trust and estate attorneys, genetic counselors, and legislators. We have already established that LTC expenses can represent a huge risk for individual’s personal financial assets. We also know that there are important wealth implications raised by LTC because many individuals who do not currently purchase LTC play to either pay out of pocket, or rely on family members for care. Thus, the role of the trust and estates bar is crucial to increasing LTC knowledge overall. Lawyers should be advising their clients about the risks LTC expenses pose to their financial well-being. Failing to account for LTC expenses today may have extreme consequences for a client tomorrow. Genetic counselors on the other hand, can inform clients about the current regulatory framework, and advise clients about the proper time to get LTC insurance. Insurance companies can disseminate information to educate their customers on how (or if) they use
genetic information for LTC policies. In this way, this policy option addresses insurer use of genetic information from the perspective of multiple stakeholders. Insureds need to know if they can be required undergo a genetic test, how that test can be used, and what the consequences could be on LTC insurance policies. Lawyers must be able to provide competent and thorough advice to their clients planning for the future. And insurance companies need the increased market participation that may follow successful education initiatives. Finally, many states have not addressed how to regulate LTC insurer use of genetic information. Increased knowledge at the policy maker level may prompt legislative action in this arena.

5. Mandate LTC Insurance Coverage and Bar Insurer Use of Genetic Information

Still another policy option exists. Nationally, policymakers could legislate a mandate for individuals to purchase LTC, and simultaneously prevent LTC insurers from using genetic information. Such an approach could combine the individual health insurance mandate of the Affordable Care Act (ACA), and the genetic information non-discrimination provisions of GINA. Such a solution would be extensive and complex, requiring legislative recognition of the condition of the LTC market, as well as the concerns associated with insurer use of genetic information.

The effects of such a vast legislative fix would undoubtedly result in a drastic increase in the amount insureds in the LTC market. This would allow LTC insurers to spread the costs and risks of those with genetic conditions to offset barring their ability to discriminate using the specific insureds genetic information. Increased participation in the market will also result in more stability. Similarly, it could reduce the risks of long-term contracting for insureds by creating a more uniform market for policies. There may be societal push back against the concept of a mandate, but as has been the case with the ACA, this is not insurmountable. Research shows
that at least some consumers support an LTC mandate. Consumers view a mandate to purchase LTC insurance as a proper mode of the government encouraging people to buy LTC, while not paying for it exclusively out of federal coffers. Finally, such expansion of the LTC market can alleviate the budgetary strain on Medicaid down the road, while simultaneously reducing the incentive of individuals to deplete their assets to become Medicaid eligible. However, such a plan may not be politically salient.

E. **Recommendation:**

Based on the unique circumstances facing the LTC market, adopting policy option D, the educational policy solution, is the best overall solution regarding genetic information use in the LTC market. The use of genetic information by insurers alone is unlikely to solve the issues facing the LTC market, because although insurers would be able to accurately price policies with actuarial justification, such use risks increasing public distrust. Distrust may in turn discourage individuals from participating in the LTC market. This policy approach creates an opportunity for insureds to learn about the risks associated with getting a genetic test and how such a test may be used for LTC insurance policies. The educational policy solution addresses both genetic information use, and presents an opportunity to increase knowledge about LTC in general, potentially increasing overall participation in the market.

V. **CONCLUSION:**

The Human Genome Project has brought vast opportunity for individuals to know more about their genetic makeup. It has also presented unanswered questions about the proper use of genetic information in life, disability, and long-term care insurance markets. Each market is unique and state legislatures have created various schemes of regulation, each with different approaches and goals. Life and disability insurance are often regulated in similar fashions, while
the fragile nature of long-term care insurance warrants separate considerations. Accordingly, this paper suggests similar policy solutions for insurer use of genetic information in the life and disability markets, while the long-term care policy solution is designed to specifically address concerns unique to its needs. Life and disability insurers should be able to consider genetic information in an actuarially-fair manner. The educational partnership policy solution for long-term care insurance better addresses both the unique underlying issues in the market and insurer use of genetic information. In each instance, policy solutions for insurer use of genetic information should be balanced, weighing the interests of insurers and individual insureds prior to implementation.

3 While the FDA warned genetic testing company 23andMe in 2014 to cease offering consumers reports that interpreted their genetic health risks, the FDA has since rescinded their warning and is now allowing 23andMe to offer interpretive reports based on the company “provid[ing] sufficient data to show that the tests are accurate.” Samantha Masunaga, What the New, FDA-approved 23andMe Genetic Health Risk Reports Can, and Can't, Tell You, LA Times (Apr. 14, 2017, 8:40 AM), http://www.latimes.com/business/la-fi-23andme-reports-20170414-htmlstory.html. The FDA also explicitly outlined that while they were allowing the service to be provided again, “the tests ‘are intended to provide genetic risk information to consumers,’ but they ‘cannot determine a person’s overall risk of developing a disease or condition.’” Id.
4 See 23andMe, https://www.23andme.com/howitworks (select “How It Works” tab, then select “See full list of reports offered” under “What services do you provide?”).
6 See id.; Casey Ross, Genetic Test Costs Taxpayers $500 Million a Year, With Little to Show for It, STAT (Nov. 2, 2016), https://www.statnews.com/2016/11/02/genetic-test-medical-costs.
8 Angelina Jolie, Opinion, My Medical Choice, N.Y. Times (May 14, 2013), http://www.nytimes.com/2013/05/14/opinion/my-medical-choice.html. Ms. Jolie also acknowledges that the cost of testing for BRCA1 and BRCA2, estimated at more than $3,000, “remains an obstacle for many women.” Id.
9 Id.
10 Gina Kolanta, New Gene Tests Pose a Threat to Insurers, N.Y. Times: Health (May 12, 2017), https://nyti.ms/2qb6v7l. Since its inception in 2007, 23andMe claims to have sold over 2 million test kits. Id.
12 Id.
require a separate event, eventually lead (2010); already been forced to address this issue as the result of institutions profiting from medical developments stemming from basic genetic defects.

However, the information contained within genetic tests can have lasting consequences on disability benefits, under the Veteran's Dioxin and Radiation Exposure Compensation Standards Act, as a result of his proximity to radioactive fallout in Japan following World War II that led to illnesses later in his life.

It would be difficult to conceive of a remedial scheme for radiation exposure that would function effectively if the results of testing or diagnosis inhibited an individual’s lifestyle or the lifestyles of that individual’s descendants. But see Victor A. McKusick, Mapping the Human Genome: Retrospective, Perspective, and Prospective, 141 PROC. AM. PHIL. SOC. 417, 420 (1997) (stating “a main justification for the HGP was its potential for identifying the basic genetic defects.”). However, the information contained within genetic tests can have lasting consequences on future generations, and its use for purposes outside of continued research, at the present moment, could be incompatible with the original aims of the HGP and efforts to redress exposure to radiation.

Understanding OUR GENETIC INHERITANCE, supra note 1. The memorandum of understanding also stated that both agencies would “share responsibility for dealing with the ethical, legal, and social implications of the genome project.” Id. at 32.

Id. at 32.

See McKusick, supra note 20, at 419.

Inst. of Med., Comm. on Assessing Genetic Risks, Assessing Genetic Risks: Implications for Health and Social Policy 254 (1994) (explaining how genetic testing has been used to create databases for individuals convicted of crimes, as well as efforts to use genetic testing in the field of genealogy) [hereinafter Assessing Genetic Risks].

Overview of the Human Genome, supra note 17.

Understanding OUR GENETIC INHERITANCE, supra note 1, at 10.

Id. at 7. The HGP budget allocated approximately five percent of its operating budget for identifying and analyzing “the ethical, legal, and social implications” of the HGP. Holmes, supra note 16, at 518.


Holmes, supra note 16.

See Holmes, supra note 16, at 565–66. While this question might seem to be purely academic, many courts have already been forced to address this issue as the result of institutions profiting from medical developments stemming from individual genetic testing. See, e.g., Moore v. Regents of the University of California, 793 P.2d 479 (Cal. 1990).


Understanding OUR GENETIC INHERITANCE, supra note 1, at 5.

McKusick, supra note 20, at 423; see GINA Findings (need citation and quote explaining that genetic research may eventually lead to the result we’re seeking).

Id. at 529–30.

Holmes, supra note 16, at 514.

Mortality is defined as the “death rate at each age as determined from prior experience.” Id. at 533 n. 71.

Morbidity is defined as the “incidence and severity of sickness and accidents in a well-defined class or classes of persons.” Id. at n.72.

The interplay of these two considerations within the area of life, long-term care, and disability insurance each require a separate analysis later in this paper.
There were some states, such as Indiana, who continued to sterilize individuals well into the 1970s. See Ind. State Bar Assoc., ‘Three Generations of Imbeciles are Enough’: A Eugenics Centennial, 1907-2007, 50 Res Gestae No. 7, 10 (2007).


See Christopher C. Faille, Imbeciles: The Supreme Court, American Eugenics, and the Sterilization of Carie Buck, book review, 63 Fed. Law. 84, No. 7 (2016)(“Filtering out the bad blood that was presumed to run through Carie Buck’s veins—so ran the theory—gave the whites, as the more suitable race, a better chance of continuing to prevail.”).


Id. at 207.

See Smith, supra note 44, at 446.

Id. at 435, 439, 446. By 1931, thirty-two states had passed statutes authorizing sterilization in at least some circumstances. See id; see also Steven I. Friedland, The Criminal Law Implications of the Human Genome Project: Reimagining a Genetically Oriented Criminal Justice System, 86 Ky. L.J. 303, 320–21 (1997)(“It is this potential for defining ‘normalcy’ - and by comparison, inferiority - through the detection and selection of genetic propensities that illuminates the great possibility of harm resulting from genetic discoveries.”)

Holmes, supra note 16, at 515.

See Cooper, supra note 41, at 357–58.

See id. at 394–95.

This differs from genetic test results which may only serve as indicators of potential illnesses later in life.

See id. at 399–400.

See id at 395–96.


See 1998 N.Y. Sess. Laws 584 § 1 (McKinney)(“In order to retain the full trust and confidence of persons at risk, the state has an interest both in assuring that HIV related information is not improperly disclosed and in having clear and certain rules for the disclosure of such information.”).

Id. at § 2781(C)(5).

Cooper, supra note 41, at 396–97.

Id. at 402; see also Holmes, supra note 16, at 573 n. 204 (describing how individuals who get tested for Huntington’s Disease often experience “survivor guilt” in the instance they test negative).

Cooper, supra note 41, at 403–04.

Holmes, supra note 41, at 529.

Dana Clay Falcone et al., Genetic Testing and Parkinson Disease: Assessment of Patient Knowledge, Attitudes, and Interest, 20 J. GENETIC COUNS. 384, 393 (2011); see also Holmes, supra note 16, at 515.


Id. at 527–29.

Id.

Id. at 539–40.

See Steven J. Schrodi et al., Genetic-Based Prediction of Disease Traits: Prediction is Very Difficult, Especially About the Future, 5 Frontiers in Genetics 14 (2014); see also Holmes, supra note 16, at 5.

Holmes, supra note 16, at 527.

Even an illness as debilitating as Parkinson’s Disease has been found to explained purely by defective genes in less than 10% of all cases worldwide. Falcone et al., supra note 64, at 384.

See Cooper, note 41, at 359.

See id. at 415.

ASSESSING GENETIC RISKS, supra note 24, at 269.


ASSESSING GENETIC RISKS, supra note 24, at 265.
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Cooper, supra note 61, at 375.

See, e.g., Moore V. Regents of the U. of California, 793 P.2d 479 (Cal. 1990).

See Cooper, supra note 61, 382–83.

See id. at 370 (noting that informed consent grew out of the case law stemming from Griswald).

ASSESSING GENETIC RISKS, supra note 24, at 265.

Id. at 262–63.

See Cooper, supra note 61, at 407.

See id. at 265.

See id. at 370 (noting that informed consent grew out of the case law stemming from Griswald).

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Colo. Rev. Stat. § 10-3-1104.7(2)(b).

Colo. Rev. Stat. § 10-3-1104.7(1)(d).

Colo Rev. Stat. § 10-3-1104.7(10)(a); see infra note 170 and accompanying text for more information about informed consent for genetic testing in Colorado.


See NCCUSL, supra, note 146, at 15-16.


See NCCUSL, supra note 146, at 15.


In one sense, this coverage already exists through the Social Security Disability Insurance system, although it is not available to all injured workers and is not a substitute for short-term disability insurance.

See Wolf & Kahn, supra note 176, at 8, 24 (noting that some genetic test results can diagnose conditions, while others can diagnose only a propensity to developing conditions, which may or may not manifest (genotypic prediction versus phenotypic manifestation). Wolf & Kahn, supra note 176, at 24.

Wolf & Kahn, supra note 176, at 8.


Id.

Id.


Id.
196 Robyn B. Nicoll, Long-Term Care Insurance and Genetic Discrimination—Get it While You’re Young and Ignorant: An Examination of Current Discrimination Problems in Long-Term Care Insurance Through the Use of Genetic Information, Albany J. of Science & Tech. 751, 763 (2003).
197 National Spending for Long-Term Services & Support, National Spending for Long-Term Services and Support (LTSS), 2012, National Health Policy Forum, 5 http://www.nhpf.org/library/the-basics/Basics_LTSS_03-27-14.pdf (Mar. 27, 2014) (estimating that the value of these services in 2011 was approximately $234 billion).
199 Reaves & Musumeci, supra note 9, at 3.
200 Medicare, U.S. Dept. of Health and Human Services, https://longtermcare.acl.gov/medicare-medicaid-more/medicare.html (last updated Oct. 10, 2017) (noting that Medicare only pays for medically necessary care, not custodial care such as bathing or supervision and that such expenses are only fully covered for the first 20 days).
202 Id.
204 Id.
205 Wenliang Hou, Wei Sun, and Anthony Webb, Why Do People Lapse Their Long-Term Care Insurance?, Ctr. for Retirement Research at Boston College 1 (2015).
208 See Long Term Care Insurance Fact Sheet, supra note 1.
210 Id.
211 Id. at 6.
215 Donald H. Taylor, Jr., et al, Genetic Testing for Alzheimer’s and Long-Term Care Insurance, 29 Health Affairs 102 (2010).
216 Id. at 104-105.
217 Id. at 106.
220 COLO. REV. STAT. ANN. § 10-3-1104.7(1)(2009).
221 Id. § 10-3-1104.7(1)(a).
222 Id. § 10-3-1104.7(3)(a).
223 Id. § 10-3-1104.7(3)(b).
224 COLO. REV. STAT. ANN. § 10-3-1108.
225 KAN. STAT. ANN. § 40-2259(d)(1).
226 Id. § 40-2259(c) (noting the prohibition of such in regards to other insurers does not apply to LTC insurers).
227 Id. § 40-2259(d)(2).
228 OR. STAT. ANN. § 746.135(1)(2017).
229 Id. § 746.135(3)-(4).
230 Id. § 746.135(4).
231 WISC. STAT. ANN. § 631.89(2).
232 Id. at § 631.89(2)(c).
233 Id. at § 631.89(d).
234 See id. at § 631.89(3)(a).
strongly agree with the statement: ‘Information from genetic tests is likely to be misused.’

Disparities

The Influence of Health Care Policies and Health Care System Distrust on Willingness to Undergo Genetic Testing

In more than one third of blacks (34%) and 28% of Latinos agree or strongly agree with the statement: ‘Information from genetic tests is likely to be misused.’

Who Buys Long-Term Care Insurance Demand Limited By Beliefs About Needs, Concerns about Insurers, and Care Available from Family, 31 Health Affairs 1294, 1299 (2012).

Taylor et al, supra note 26, at 107.

24–A ME. REV. STAT. ANN. § 2159–C(3).

Id.

Id. at § 2159-C(3)(A).

Id. at § 2159-C(3)(B).


Id. § 18-120(4)(b)(5).

Id. § 18-120(4)(c).


Id. at §108I(a).

Id. at §108I(c).

Id.

Id. at §24-21-3(D).

Id.

Id. at § 9334(a).

Id. at § 9334(b); see also 8 VT. ST. ANN. ch. 129, § 4724(7)(D).

8 VT. ST. ANN. ch. 129, § 4724(7)(D).

Id.

Id.


Idaho Code § 41-1313.


N.Y. Ins. Law § 2615(c).


See State v. Lyons, 924 P.2d 802, 806 (Or. 1996).


Id.

Jeffrey R. Brown, Gopi Shah Goda, and Kathleen McGarry, Long-Term Care Insurance Demand Limited By Beliefs About Needs, Concerns about Insurers, and Care Available from Family, 31 Health Affairs 1294, 1299 (2012).

Who Buys Long-Term Care Insurance in 2010-2011, AHIP 43-45, https://LTChorse.com/wp-content/uploads/2015/07/Who-Buys-LTC-Insurance-2010-2011.pdf (noting that the majority of Americans over age 50 think the government should encourage the purchase of LTC through means such as tax incentives, but that the government should not itself pay for the coverage).

Brown, Goda & McGarry, supra note 86 at 1294.

Katrina Armstrong, et al. The Influence of Health Care Policies and Health Care System Distrust on Willingness to Undergo Genetic Testing, 50 Med. Care 381, 383 (finding that disclosure of genetic test results to an insurance company had the greatest negative influence on an individual’s likelihood to undergo a genetic testing).

See id.

Sandra Suther and Gebre-Egziabher Kiros, Barriers to the Use of Genetic Testing: A Study of Racial and Ethnic Disparities, 9 Genetics in Med. 655, 660 (“[M]ore than one third of blacks (34%) and 28% of Latinos agree or strongly agree with the statement[... ‘Information from genetic tests is likely to be misused.’].”
See supra Part II.C.

Taylor et al, supra note 26, at 106.

Cramer and Jensen, supra note 25, at S186.

Id.

Id. at S190.

Id. at S191.


Id. at 51.

See supra Part II.


For the individual coverage mandate of the ACA and associated penalties for failing to have coverage, see 26 U.S.C. § 5000A. For the ban of insurer use of genetic information in health insurance plans, see 26 U.S.C § 9802(a)(1)(F).

Allaire, Brown & Weiner, supra note 14, at 6 (noting minorities and those with fair to poor health have a higher preference for mandating LTC insurance).

Brown, Goda, & McGarry, supra note 86, at 1294.